

DEPARTMENTS OF LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES  
APPROPRIATIONS FOR 2010

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HEARINGS  
BEFORE A  
SUBCOMMITTEE OF THE  
COMMITTEE ON APPROPRIATIONS  
HOUSE OF REPRESENTATIVES  
ONE HUNDRED ELEVENTH CONGRESS  
FIRST SESSION

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SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

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NOTE: Under Committee Rules, Mr. Obey, as Chairman of the Full Committee, and Mr. Lewis, as Ranking  
Minority Member of the Full Committee, are authorized to sit as Members of all Subcommittees.

CHERYL SMITH, SUE QUANTIUS, NICOLE KUNKO,  
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**PART 6**  
**STATEMENTS OF MEMBERS OF CONGRESS AND OTHER**  
**INTERESTED INDIVIDUALS AND ORGANIZATIONS**



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## Part 6



**DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES APPROPRIATIONS FOR 2010**



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SERVICES, EDUCATION, AND RELATED AGENCIES  
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**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION, AND RE-  
LATED AGENCIES APPROPRIATIONS FOR  
2010**

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TESTIMONY OF INTERESTED INDIVIDUALS AND  
ORGANIZATIONS

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WEDNESDAY, MARCH 18, 2009.

Mr. OBEY. Well, good morning, everyone. Thank you all for coming. I am pleased to open the Subcommittee's first hearing for the new fiscal year.

Let me first start by welcoming our new Ranking Member, Todd Tiahrt. He and I have long experienced changing tires with each other in the middle of nowhere, and I am looking forward to our relationship on this Subcommittee.

I also want to welcome the other new members of the Subcommittee: Congressman Jim Moran; we have a returning member, Congressman from Montana, Mr. Rehberg; we also are being joined by Congressman Rodney Alexander; Congressman Jo Bonner; and Congressman Tom Cole from—I cannot say it is my home State, but it is my birth State—Oklahoma.

We are happy to have all of them on the Subcommittee.

We are starting off the hearings for this Subcommittee at a time when the Country is in a deep recession, and that impacts people all throughout the Country. I am sure we will see evidence of that by people's testimonies here today.

We are somewhat handicapped because any time you have a new President, that sort of discombobulates the budget schedule. With a new President, they want time to prepare their own budget, so we are not yet in receipt of the President's budget, which I understand will be coming down some time this year. [Laughter.]

I hope it comes down sooner than that. And, when it does, we will deal with it in as much depth as time permits so that we can try to stay on schedule this year.

We also hope that the Budget Committee will move its product ahead in a timely fashion so that we can meet our own schedule.

I am going to ask every witness to please adhere to the four minute limit. We are not trying to be rude, but if you do not adhere to the four minute limit, there are other people who will not get a chance to testify, because we are going to be interrupted from time to time by things called roll calls. This would be a great job if we did not have to interrupt our work to go vote once in a while,

but, unfortunately, we have to, so I would ask for your cooperation. I appreciate your being here today.

With that, I would turn to Congressman Tiahrt for whatever comments he would like to make.

Mr. TIAHRT. Thank you, Mr. Chairman. It is a pleasure to join you on this Committee. I am looking forward to the interesting work that you have been carrying on. I know that this Committee has been a passion of yours, so I know that you will reflect that and the witnesses that we get to hear from. I am pleased to be joined by my members here. I think the way you explained this birth in Oklahoma and end up in Wisconsin was I was born in Oklahoma by the grace of God, I am a Wisconsinian.

Mr. OBEY. I think that is how that worked, Todd. [Laughter.]

Mr. TIAHRT. I know we have a full schedule today. I am looking forward to working with the members and listening to the testimony. Thank you, Mr. Chairman.

Mr. OBEY. I should explain. I have explained to people many times. My father was the only man in America who moved to Oklahoma during the Depression to get a job. [Laughter.]

I also want to just bring to the attention of our new members, as well as the audience, the pictures on the wall there. What we have tried to do in this Committee is to remind people that this Subcommittee has a distinguished heritage, and the heritage is best exemplified by the members on the wall, starting with John Fogerty up on the left, who chaired this Subcommittee for many years. He was a bricklayer by profession before he fell into a life of sin and got elected to Congress. His ranking member for many years was Mel Laird, who was my predecessor in the Congressional district that I now hold.

If you take a look at the men pictured there, you will see a history of bipartisanship and a history of doing some really remarkable things for the Country. This Subcommittee, in the past, oversaw the spectacular growth of the National Institutes of Health; the birth of the Department of Health, Education, and Welfare; the splitting up of that agency; the creation of the Department of Education; and very major changes in budget trends in the Country through the years. I would hope that we can continue that tradition.

With that, our first witness will be introduced by the gentleman from Illinois, Mr. Jackson.

Mr. JACKSON. Thank you, Mr. Chairman. Let me also congratulate you and thank you for the pictures that you have hung in the Subcommittee hearing room. It gives me something to aspire to. I can see that I am still probably 30 or 40 years away having my picture hung. [Laughter.]

Mr. OBEY. Members are generally hung before their pictures are. [Laughter.]

Mr. JACKSON. Thank you, Mr. Chairman. Let us hope that is not the case.

It is my pleasure to welcome Mr. J.B. Pritzker to our Subcommittee. Mr. Pritzker is a partner of and founded New World Ventures in 1996 and is also a managing partner of the Pritzker Group. Mr. Pritzker also heads the J.B. and M.K. Pritzker Family Foundation, a Chicago-based philanthropy. The Foundation is a

private family foundation deeply committed to the pursuit of social justice and to shaping innovative and effective strategies for solving society's most challenging problems.

As Mr. Pritzker will describe, The Children's Initiative, a project of the J.B. and M.K. Pritzker Family Foundation, seeks to enhance the early learning capabilities of infants and toddlers, with a special focus on at-risk children. Inspired by the early childhood development work of the late Chicago entrepreneur and philanthropist Irving Harris, and motivated by the relief and the belief that all children are born with great potential, The Children's Initiative supports policies, programs, research, and advocacy to allow at-risk children to achieve better economic, educational, and social outcomes.

Mr. Chairman, a number of us back in Chicago have worked with J.B. for a number of years. We have, at various moments in his philanthropic career, encouraged him to consider entering this body. He would make a fine United States Representative and certainly, if he ever desired, a fine member of the other body.

Ladies and gentlemen, Mr. Chairman, Mr. J.B. Pritzker.

Mr. OBEY. I could not understand why anyone would ever want to be a member of the other body, but that is beside the point. [Laughter.]

Mr. Pritzker, you are recognized for four minutes.

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WEDNESDAY, MARCH 18, 2009.

## THE CHILDREN'S INITIATIVE

### WITNESS

#### J.B. PRITZKER

Mr. PRITZKER. Thank you, Mr. Chairman. Fortunately, I do not live in the 2nd Congressional District, so my chances are improved somewhat if I ever decide to do that.

Thank you, Chairman Obey, for inviting me to be here today. It is a great honor to sit here in front of you as a champion of children and the disadvantaged. You have done so much and I am personally very grateful.

Congressman Jackson, thank you for the kind introduction. Our long personal relationship goes back probably even before you may remember, to when I worked for Senator Terry Sanford and you were on the campaign trail or working with your dad, and the two of them met early morning in a hotel room in North Carolina to talk about the future of the Democratic Party. So I got to be witness to maybe your political birth.

Thank you also to the entire Committee for your advocacy on behalf of disadvantaged children, for all the wonderful successes that you have already accomplished this year and for all that you do and will do for our Nation's children.

In my day job, I worry non-stop about making good investments about building businesses and growing capital, and behind you on the wall, Chairman Obey, I understand you had painted on the wall the quote from Hubert Humphrey that begins "The moral test of government is how it treats those who are at the dawn of life,

the children.” I might add, for everybody else, that it is also the mark of a fiscally responsible Government to invest in early childhood.

In my philanthropic work, I have similar goals, that is, to make good investments. I face far less worry, of course, in that, and enjoy much more certainty. By supporting early childhood education, I know I am making an investment in fostering human capital that is guaranteed to pay dividends.

We all know that everyone is born with potential, but we often do not have the facts to say how much society should invest in maximizing potential from an early age or whether financial risk makes sense. Well, finally, the work of economists like Nobel Laureate Jim Heckman, at the University of Chicago, developmental psychologists, sociologists, statisticians, and neuroscientists provides the answer with decades of research, solid data, and multidisciplinary analysis.

Investing in early childhood development for disadvantaged children and their families provides a real return on investment, around 10 percent—it has been calculated by not liberal, but even conservative economists—through increased personal achievement and social productivity. It improves the health, economic and social outcomes not just for individuals, but for society at large.

In these complicated and tumultuous times, we face a litany of problems we would like to fix and goals we would like to achieve: fostering economic competitiveness; achieving better educational outcomes; increasing the opportunity for health; reducing crime; building a capable, productive, and competitive workforce. Anyone looking for upstream solutions for the biggest problems facing America should understand that the great gains to be had by investing in early and equal development of human potential exists in investing in early childhood.

If I leave you with nothing else today, I hope you will take away the following: Your efforts in early childhood development are an investment yielding real dollar returns. Early childhood development is not just an education issue, it is also a health issue that affects the health of our economy. A vast body of research shows that early childhood development from the ages of zero to five greatly affects cognitive development, social and emotional health, and the ability to learn as a child and later function at a high level as an adult. Effective early childhood development has the potential to reduce teen pregnancy, crime, and other social burdens, while increasing human productivity that drives economic security for all. It will produce a smarter, stronger, healthier, and more prosperous Nation, helping America stay the top competitor in the global economy.

In the long run, it will cost us less than it is costing us now to remediate the consequences we suffer by not providing effective early childhood development investment.

Mr. OBEY. Could I ask you to wind up, because your time has expired?

Mr. PRITZKER. Yes, sir.

We know our investments need to begin at birth and have a particular focus on infants and toddlers, who currently have the greatest needs and receive the fewest services.



Implementing effective early childhood education programs can be done because it is being done, with measurable results. I invest in Educare of Chicago. It is one solution to this. It is the gold standard of high quality early education, providing full day, full year care and education for disadvantaged children from birth to five with high quality and highly qualified teachers.

Thanks to the investments made in American Recovery and Reinvestment Act, you have provided a down payment to help serve more children and improve the quality of the education they are receiving. But there is much more to be done. For millions more children in poverty who do not have access to early learning opportunities, closing that disadvantage gap would prove to be of great advantage to all Americans. Please continue to support Head Start, Early Head Start, the Child Care and Development Block Grant, and the President's Early Learning Challenge Grants.

We do not have to reinvent the wheel when it comes to effective early childhood development programs; we simply need to get the wheel rolling across America to benefit all.

Thank you very much.

Mr. OBEY. Thank you very much.

[The information follows:]



**Statement**

**J.B. Pritzker**

**Founder, J.B. and M.K. Pritzker Family Foundation**

**Chicago, Illinois**

**Testifying on behalf of the First Five Years Fund**

**Regarding Investments in High Quality Early Childhood Education**

**In the Departments of Health and Human Services and Education**

**SUMMARY**

In my day job, I worry non-stop about making wise investments and growing capital. In my philanthropic work, I have the same goals, but I face far less worry and enjoy much more certainty. By supporting early childhood education, I know I'm making an investment in fostering human capital that is guaranteed to pay dividends. The work of economists, developmental psychologists, sociologists, statisticians, and neuroscientists have documented with decades of research, solid data and multi-disciplinary analysis that investing in early childhood development for disadvantaged children and their families provides a 10% return on investment through increased personal achievement and social productivity. It improves the health, economic, and social outcomes not just for individuals, but for society at large.

In these complicated and tumultuous times, we face a litany of problems we'd like to fix and goals we'd like to achieve. Anyone looking for upstream solutions to the biggest problems facing America should understand the great gains to be had by investing in early and equal development of human potential. In the long run, it will cost us less than it is costing us now to remediate the consequences we suffer by not providing effective early childhood development. Investing early –starting at birth - amounts to “fixing it before it's broken” and gives us better value for our dollars.

There is much more to be done for millions more children in poverty who don't have access to high quality early learning opportunities. Closing that disadvantage gap would prove to be of great advantage to all Americans. Please continue to support Head Start, Early Head Start, the Child Care and Development Block Grant, and the President's Early Learning Challenge Grants.



**Statement**  
**J.B. Pritzker**  
**Founder, J.B. and M.K. Pritzker Family Foundation**

Thank you, Chairman Obey, for inviting me here today. It's an honor to appear before such a wonderful champion of children and the disadvantaged. Thank you, Congressman Jackson, for that kind introduction. Thank you, too, to Congresswoman DeLauro and to the entire Committee for your advocacy on behalf of disadvantaged young children—for all of the wonderful success you've already accomplished this year, and for all that you will do as you continue to strive for the very best for our nation's children.

In my day job, I worry non-stop about making wise investments and growing capital. In my philanthropic work, I have the same goals, but I face far less worry and enjoy much more certainty. By supporting early childhood education, I know I'm making an investment in fostering human capital that is guaranteed to pay dividends.

We all know that everyone is born with potential, but we often don't have the facts to say how much society should invest in maximizing potential from an early age—or whether the financial risk makes sense. The work of economists, developmental psychologists, sociologists, statisticians, and neuroscientists provides the answer with decades of research, solid data and multi-disciplinary analysis. Investing in early childhood development for disadvantaged children and their families provides a 10% return on investment through increased personal achievement and social productivity. It improves the health, economic, and social outcomes not just for individuals, but for society at large.

In these complicated and tumultuous times, we face a litany of problems we'd like to fix and goals we'd like to achieve: Fostering economic competitiveness. Achieving better educational outcomes. Increasing the opportunity for health. Reducing crime. Building a capable, productive and competitive workforce. Anyone looking for upstream solutions to the biggest problems facing America should understand the great gains to be had by investing in early and equal development of human potential.

Early childhood development is not just an education issue—it is also a health issue that affects the health of our economy. A vast body of research shows that early childhood development from the ages of zero to five greatly affects cognitive development, social and emotional health, and the ability to learn as a child and later function at a high level as an adult. Effective early childhood development has the potential to reduce teenage pregnancy, crime, and other social burdens while increasing human productivity that drives economic security for all. It will produce a smarter, stronger, healthier, and more prosperous nation—helping America stay the top competitor in a globally competitive

society. In the long run, it will cost us less than it is costing us now to remediate the consequences we suffer by not providing effective early childhood development. Investing early amounts to “fixing it before it’s broken,” and gives us better value for the dollars we devote to social supports.

There is evidence that the achievement gap we worry so much about in school-age children actually emerges before children are 18 months old and, without intervention, only continues to widen over time. This, then, is not an “achievement gap”: it’s an opportunity and access gap. When we fail to close this gap and fail to relieve the burden of disadvantage among children, we create costly social burdens that affect us all.

We know our investments need to begin at birth and have a particular focus on infants and toddlers, who currently have the greatest needs and receive the fewest services. The federal government and states have developed a range of programs of differing quality. It is critically important that we look at which programs are most effective and why, and work to implement them where they are needed most. We urge the federal government to work with states to develop comprehensive, high-quality early childhood development programs that are easily accessible and affordable to disadvantaged children and their parents.

Implementing effective early childhood education programs can be done because it is being done—with measurable results. I invest in Educare of Chicago. It’s the gold standard of high quality early education, providing full-day, full-year care and education for disadvantaged children from birth to five with highly-qualified teachers as well as a full range of family supports to help parents be active partners in their children’s development. Educare is a public-private partnership that relies on Head Start, Early Head Start, and child care funding to serve at-risk children. It was built in the shadow of the Robert Taylor Homes public housing project, in what was at the time the poorest census tract in the United States. I’m enormously proud to say that the children who enter Educare when they are very young emerge from the program with vocabularies and school readiness scores that meet and exceed national averages. We put them on a level playing field with advantaged, middle-class children. We closed the achievement gap by closing the opportunity gap.

Thanks to the investments made in the American Recovery and Reinvestment Act, you have provided a down payment to help serve more children and improve the quality of the education they’re receiving. But there is much more to be done for millions more children in poverty who don’t have access to the early learning opportunities they need. Closing that disadvantage gap would prove to be of great advantage to all Americans. Please continue to support Head Start, Early Head Start, the Child Care and Development Block Grant, and the President’s Early Learning Challenge Grants.

We don’t have to reinvent the wheel when it comes to effective early childhood development programs, we simply need to get the wheel rolling across America—for the economic benefit of all.



### **J.B. PRITZKER**

Mr. Pritzker is a Partner of and founded New World Ventures in 1996, which has become one of Chicago's prominent early-stage technology fund managers. He is also Managing Partner of The Pritzker Group. A founding board member of the Illinois Venture Capital Association, a founding director of the Chicagoland Entrepreneurial Center, and a member of the Young Presidents' Organization, Pritzker has been a forceful and active proponent of a stronger technology base in the Midwest region.

Crain's Chicago Business honored Mr. Pritzker with the designation as a business leader in its "40 under 40," and "Who's Who of Chicago Business." The Chicago Sun-Times named him to their "Hot 100" most prominent members of Chicago's technology economy, and he is ranked #160 among Forbe's 400 Richest Americans. The City Club of Chicago awarded him Citizen of the Year, and he received the Humanitarian Award from the Holocaust Memorial Foundation of Illinois for his philanthropic activities.

Pritzker is a trustee and serves on the investment committee of Northwestern University and is a member of the Board of Governors of the Northwestern University School of Law. Appointed by the Governor of Illinois, he serves as Chairman of the Illinois Human Rights Commission and was co-Chairman of the Governor's Transition Committee for Civil Rights. He is also Chairman of the Illinois Holocaust Museum Campaign. Pritzker is an attorney and a member of the Illinois and Chicago Bar Associations. He graduated with an A.B. in political science from Duke University and earned his J.D. from Northwestern University School of Law. He lives in Evanston, Illinois with his wife and family.

Mr. Pritzker heads the **The J.B. and M.K. Pritzker Family Foundation**, a Chicago-based philanthropy. The Foundation is a private family foundation deeply committed to the pursuit of social justice and to shaping innovative and effective strategies for solving society's most challenging problems.

**The Children's Initiative**, a project of the J.B. and M.K. Pritzker Family Foundation, seeks to enhance the early learning capabilities of infants and toddlers, with a special focus on at-risk children. Inspired by the early childhood development work of the late philanthropist Irving Harris and motivated by the belief that all children are born with great potential, The Children's Initiative supports policies, programs, research, and advocacy to allow at-risk children to achieve better economic, educational and social outcomes.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

J.B. Pritzker  
The Pritzker Group  
1603 Orrington Ave. Suite 1600  
Evanston, IL 60201

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

First Five Years Fund

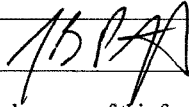
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes

☒ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

Signature:



Date:

3/18/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Next, Mr. Ryan.

Mr. RYAN. Thank you, Mr. Chairman. I would like to take this opportunity to introduce Linda Lantieri, who is going to testify. She is on behalf of the Collaborative for Academic Social and Emotional Learning. This is a collaborative that actually exists in Congressman Jackson's district at the University of Illinois at Chicago.

Let me just quickly say I think this is a transformational education program for our country, and this is based on a lot of the research and work that was done from the book Emotional Intelligence by Dan Goldman, and this is something, Mr. Chairman, that I am taking up now as a personal mission in my life to support you.

With that, Ms. Lantieri.

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WEDNESDAY, MARCH 18, 2009.

## **COLLABORATIVE FOR ACADEMIC, SOCIAL AND EMOTIONAL LEARNING**

### **WITNESS**

#### **LINDA LANTIERI**

Ms. LANTIERI. Thank you, Congressman Ryan.

I appreciate the opportunity to speak to you today from the perspective and experience of someone who has been in the field of education for four decades, as a classroom teacher and administrator in East Harlem, and as education faculty at Hunter College, New York City. More recently, I have been deeply involved in the healing and recovery efforts in 12 schools in Lower Manhattan in which 8,000 children and 200 teachers fled for their lives on the fourth day of school, September 11th, 2001.

Today, I am representing the Chicago-based Collaborative for Academic, Social, and Emotional Learning. CASEL is the world's leading organization advancing research, school practice, and public policy to establish social and emotional learning as an essential part of education, pre-K through 12.

The field of social and emotional learning is informed by scholarly research that demonstrates that the systemic teaching of emotional and social skills as part of a student's regular school day adds to the lessons needed for life: improving self-awareness and confidence, managing disturbing emotions and impulses, increasing empathy and cooperation. These skills also provide students with the essential tools they actually need to be effective learners as well.

A recent review of 31 studies on social and emotional learning showed that improvements in students' academic scores were an average of 11 percentile points over students who did not receive social and emotional learning. For example, one of the studies in the review that by the time they were 18, students who received social and emotional learning in grades 1 through 6 had significantly higher grade point averages, showed lower school misbehavior and delinquency, and showed lower heavy alcohol use from students who were in the control group.

The academic and life success returns on the investment in SEL are substantial. These are also the same very skills that our Nation's business and government leaders have defined as essential for effectiveness in the modern workplace.

I am happy to say that Illinois and New York have already passed legislation and released guidelines to move this agenda forward. However, too few students have access to this critical programming, and the schools that do need training and technical assistance so their SEL efforts are maximized.

Because SEL requires serious commitment at the Federal, State, school district, and community levels, CASEL is advising in the development of authorizing legislation to support SEL programming in the field. The proposed legislation would establish both a National Training and Technical Assistance Center and a State and local grant program to promote SEL nationwide.

We look forward to sharing with you more about this as this proposed legislation progresses.

There is, however, much we can do right now to further this agenda by using existing Federal funding. I ask you to support report language to the Labor, HHS, Education Appropriations bill that will encourage States and local agencies to use Federal funds for SEL programming, particularly as part of Title I school improvement, Title II teacher quality enhancement, and effective use, of course, of Title IV, Safe and Drug Free Schools funding.

Unfortunately, many of our young people today would describe school as a place that prepares them for a life of tests, instead of preparing them for the tests of life. I hope you agree with me that we can do better, and I thank you for the opportunity to speak to you today.

Mr. OBEY. Thank you very much, and thank you for staying within the time.

Ms. LANTIERI. You are very welcome.

[The information follows:]



Linda Lantieri  
Director, Inner Resilience Program  
New York, New York

Subcommittee on Labor, Health and Human Services, Education,  
and Related Agencies

Wednesday, March 18, 2009 10:00 AM

Collaborative for Academic, Social and Emotional Learning  
(CASEL)

This testimony will discuss the importance and value of advancing research, school practice, and public policy focused on the development of children's social and emotional competence and establishing Social and Emotional Learning (SEL) as an essential part of education, from preschool through high school. It will include suggestions on how this mission could be assisted through federal authorizing legislation to support SEL training and technical assistance and pilot sites nationwide, and will ask for support for report language to the Labor-HHS-Education Appropriations bill to use federal funds for SEL programming under Title I school improvement programs, Title II teacher quality enhancement, and Safe and Drug Free School funding.

Testimony of Linda Lantieri on behalf of the Collaborative for Academic, Social, and Emotional Learning (CASEL) [www.CASEL.org](http://www.CASEL.org)

I appreciate the opportunity to speak to you today from the perspective and experience of someone who has been in the field of education in a variety of roles for four decades – as a classroom teacher and administrator in East Harlem and education faculty member at Hunter College, NYC. More recently, I have been deeply involved in the healing and recovery efforts in twelve schools in lower Manhattan in which over 8,000 children along with their 200 teachers fled for their lives on the 4<sup>th</sup> day of school on September 11, 2001.

Today I am representing the Collaborative for Academic, Social, and Emotional Learning (CASEL), the world's leading organization advancing research, school practice, and public policy focused on the development of children's social and emotional competence. Our mission is to establish Social and Emotional Learning as an essential part of education, from preschool through high school.

Often called the “missing piece” in school improvement efforts, the field of Social and Emotional Learning (SEL) reflects the growing recognition that healthy social and emotional development advances children's success in school and life. SEL is informed by scholarly research demonstrating that all children can have a school experience that helps them be not only academically competent but one that supports them in being engaged life-long learners who are self-aware, caring, and connected to others, and who contribute actively to building a more just, peaceful, productive, and sustainable world.

SEL programming addresses five essential areas of social and emotional development:

1. ***Self-awareness*** (recognizing one's capacities, strengths, emotions, and values)
2. ***Self-management*** (managing emotions and behaviors, persevering in overcoming obstacles)
3. ***Social awareness*** (showing understanding and empathy for others)
4. ***Relationship skills*** (forming positive relationships, teamwork, conflict resolution)
5. ***Responsible decision-making*** (making ethical, constructive choices about personal and social behavior)

Such skills provide students the essential tools they need to be effective learners - including such skills as: focusing attention, setting and persisting toward goals, working effectively with others, making good decisions, creative problem-solving, and negotiating.

In classrooms from Anchorage, Alaska to NYC, SEL skills are being taught to students of diverse backgrounds in pre-kindergarten to grade 12, by regular classroom teachers, as a regular part of their school experience. Rigorous research has clearly established that students who are exposed to SEL programming exhibit: greater motivation to learn and commitment to school; decreased misbehavior and aggression; and improved attendance, graduation rates, grades and test scores.

*Testimony of Linda Lantieri on behalf of CASEL*

A recent review of 31 studies found that **Social and Emotional Learning results in improvements in students' achievement test scores - by an average of 11 percentile points over students who did not receive Social and Emotional Learning programming.** The magnitude of this impact and the strength of the research base behind it, are significant. As a point of comparison, studies of the impacts of reducing class size show smaller academic gains as a result than does SEL instruction. In challenging economic times, when cost cuts may require painful teacher layoffs, the payoff for investing in children's social and emotional development are real and sizable. For example, one major multi-year study found that by the time they were adults, students who received Social and Emotional Learning in grades 1-6 had an 11 percent higher grade-point average and significantly greater levels of school commitment, attachment, and completion at age 18.

The same research showed that the retention rate of students who received Social and Emotional Learning in grades 1-6 was 14 percent, versus 23 percent of students in a control group. At age 18, students in the same study showed a 30 percent lower incidence of school behavior problems, a 20 percent lower rate of violent delinquency, and a 40 percent lower rate of heavy alcohol use. Clearly, the decision-making and self-mastery skills these students learned early in life paid off greatly as they grew older and encountered life's increasingly complex and challenging choices. The "ROI in SEL" - that is, the academic and life-success returns on investment in SEL - are substantial.

Many of the skills that our nation's business and government leaders have defined as essential for effectiveness in the modern workplace - the ability to function as part of a team, work with diverse colleagues and customers, analyze and generate solutions to problems, persist in the face of challenging setbacks - are social and emotional skills. I have seen first hand how these skills can form a foundation for young people's success not just in school, but also as productive workers, as parents, and as citizens.

There are many examples of school districts across this country that have made Social and Emotional Learning integral to their vision of what it means to be an educated person. Both the states of Illinois and New York have already passed legislation and adopted guidelines to move this agenda forward. Outstanding examples abound of SEL practice in schools throughout this country. However, model schools and school districts are still the exception not the norm. Far too few children have access to this critical programming that provides them with sequenced Social and Emotional Learning instruction using active learning strategies that focus on developing specific social-emotional skills.

Because SEL requires serious and committed federal, state, district, and principal leadership, long-term professional development of teaching staff and school mental health personnel, parent engagement, and classroom instruction, CASEL is assisting in the development of authorizing legislation to support SEL programming from the federal level. The proposed legislation would establish both a National Training and Technical Assistance Center and a state and local grant program to promote SEL nationwide. This Center would support the development of Social and Emotional Learning standards, programs, and practices for states and local educational agencies, including technical assistance on how to engage families and communities in Social and Emotional Learning efforts. It would also provide ongoing professional development, conduct research, and disseminate reliable assessment tools to measure student progress in social and

*Testimony of Linda Lantieri on behalf of CASEL*

emotional development and evaluate Social and Emotional Learning programs to document the impact of such programs on student achievement and behavior. We look forward to sharing this proposed legislation with you when we have finished that process.

The good news, however, is that there is also much that can be done using existing federal funding to further the SEL agenda. I ask your support for report language to the Labor-HHS-Education Appropriations bill that will encourage states and local educational agencies to use federal funds for SEL programming, particularly as part of their Title I school improvement programs, as part of their Title II teacher quality enhancement and as an effective use of Safe and Drug Free Schools funding under Title IV. We at CASEL believe that SEL can be the umbrella under which school systems can bring to the table functions that traditionally are fragmented in school systems - health, youth development, counseling, service learning, specialized services, and postsecondary initiatives. In the current harsh economic environment, solutions that coordinate and thus extend the reach of separate resource pools are more needed than ever before.

Over the past several years, many of our young people throughout this country would unfortunately describe their school experience as one that prepares them for "a life of tests" rather than one which is preparing them for "the tests of life." I hope you agree with me that we can do better. I would like to conclude by telling you about a young man who I met over 20 years ago who was one of the best SEL teachers I ever had. Eugene went to a struggling high school in the South Bronx that became very committed to providing young people with skills in Social and Emotional Learning as a regular part of their curriculum. One day however Eugene was in the wrong place at the wrong time. He was on a corner in his neighborhood with his girlfriend and realized out of the corner of his eye that the car turning the corner was going to be a drive by shooting. He quickly pushed his girlfriend to the ground and took the bullet.

When I went to Metropolitan Hospital to visit Eugene three days after that, I walked into a hospital ward where I saw more than 30 young men who looked like Eugene who were in wheelchairs, paralyzed for life from the killing fields of NYC. When I got a chance to finally be alone with Eugene, I asked him how he was doing. He said that he was feeling terrible until this morning. So naturally I asked him what had happened to change that around for him. He proceeded to say that this morning he woke up and decided to forgive the guy who pulled the trigger that paralyzed him because he realized that he could have been the kid who pulled that trigger if I hadn't taught him that there was another way.

I look forward to the day when we can assure our young people that they will receive *all* of what they need to be the caring, loving and committed citizens we want and need them to be. Our job is to make sure we teach them that there is another way. Thank you for the opportunity to speak to you today.

### **Biography of Linda Lantieri**

**Linda Lantieri, MA** is a Fulbright Scholar, keynote speaker, and internationally known expert in social and emotional learning, conflict resolution, inter-group relations, and crisis intervention. Currently she serves as the Director of The Inner Resilience Program, a project of the Tides Center. She is also the cofounder of the Resolving Conflict Creatively Program (RCCP), which has been implemented at 400 schools in 15 school districts in the United States, with pilot sites in Brazil and Puerto Rico. Started in 1985, RCCP is now one of the largest and longest running research-based (K-8) school programs in Social and Emotional Learning (SEL) in United States. Linda is also one of the founding board members of the Collaborative for Academic, Social, and Emotional Learning (CASEL) whose central office is in Chicago. CASEL's mission is to establish Social and Emotional Learning as an essential part of education from preschool through high school worldwide.

Linda has 40 years of experience in education as a former teacher, assistant principal, director of an alternative middle school in East Harlem, and faculty member of the Department of Curriculum and Teaching at Hunter College in New York City. She has served as a consultant to various institutions in the area of death education, including the Mount Sinai School of Medicine and the New York City Public Schools where she trained the first Crisis Response Teams in 1988. She is a Board Certified Expert in Traumatic Stress from the American Academy of Experts in Traumatic Stress.

Linda is the coauthor of *Waging Peace in Our Schools* (Beacon Press, 1996), editor of *Schools with Spirit: Nurturing the Inner Lives of Children and Teachers* (Beacon Press, 2001), chapter contributor to *Forever After: New York City Teachers on 9/11* (Teacher College Press, 2006), and author of *Building Emotional Intelligence* (Sounds True, 2008). She was selected as an Educational Innovator by the National Education Association, received the Richard R. Green Distinguished Educator Award and the Spirit of Crazy Horse Award for "creating courage in discouraged youth." She also received the International Education and Resource Network (iEARN) 2001 Making a Difference Award.

Linda is a Senior Scholar at the Fetzer Institute, a nonprofit organization that supports research and education in the relationship between body, mind, and spirit. She is a Fellow of the George Lucas Educational Foundation and also serves as a Senior Educational Advisor of Operation Respect, which was founded by Peter Yarrow of Peter, Paul and Mary.

#### **Linda Lantieri**

#### ***Founding Board Member***

#### **Collaborative for Academic, Social, and Emotional Learning (CASEL)**

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**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

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212-509-0022 Ext. 226

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Collaborative for Academic, Social and Emotional Learning (CASEL)

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes      No ☒

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

Signature:



Date: March 16, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

WEDNESDAY, MARCH 18, 2009.

**CENTER FOR LAW AND SOCIAL POLICY**

**WITNESS**

**DANIELLE EWEN**

Mr. OBEY. Next, Center for Law and Social Policy, Danielle Ewen.

Ms. EWEN. Chairman Obey, members of the Subcommittee, thank you for the opportunity to testify today about the importance of continuing to grow Federal investments in Head Start and Early Head Start in order to support our most vulnerable: infants, toddlers, preschoolers, and their families. Your support for these birth to five programs, most recently demonstrated by the funding increases they received in the economic recovery package, has long been critical to their success.

I am testifying today on behalf of the Center for Law and Social Policy, or CLASP. CLASP is a national nonprofit that works to improve the lives of low-income people. CLASP's mission is to improve the economic security, education and workforce prospects and family stability of low-income parents, children, and youth, and to secure equal justice for all.

As you know, Head Start and Early Head Start are the only federally-funded programs providing comprehensive early education and support services for poor children and their families. Both Head Start and Early Head Start have proven their effectiveness in national studies that show gains in cognitive development and physical and mental health. More importantly, both programs have proven their effectiveness by improving the lives of children and families.

Head Start and Early Head Start serve a diverse array of children and families living in poverty. Seventy-seven percent of participants across all Head Start funded programs are in families earning below the Federal poverty level. Another 15 percent qualify because they receive public assistance. Thirty-one percent of participants in the programs come from homes where English is not the primary language. A greater proportion of African-American and Latino children participate in Head Start than do white or Asian children.

One-third of all parents with children in Head Start have less than a high school diploma or GED. But Head Start and Early Head Start families are working hard to become self-sufficient. Seventy percent of all Head Start families include at least one working parent, and 13 percent of families include a parent in school or job training. Yet, despite their best efforts, most of these families still live in poverty and lack access to basic supports.

We know that children living in poverty face many risk factors to healthy development, risks that often go undetected until the children enter school. The majority of participating families receive health and social service referrals through Head Start. Eighty-four percent of families in Early Head Start and 73 percent in Head Start accessed at least one service in 2008. Importantly, half of all children in Head Start with disabilities were diagnosed during the program year. Without the intervention of the program, it is likely

that these issues would have gone undetected until children entered kindergarten or even first grade.

To expand their reach, Head Start providers are partnering with State pre-kindergarten, child care, and other early childhood programs to provide high quality full day and year experiences.

In Hamilton County schools in Chattanooga, Tennessee, the school district uses Title I funds in conjunction with Head Start funds to expand the availability of high quality classrooms.

In Birmingham, Alabama, the Head Start agency has partnered with family child care providers to provide Head Start services in family child care homes. Providers are trained in the model and receive the full range of professional supports. Providers also meet all of the performance standards for every child and are monitored on a regular basis.

Yet, even as they leverage as much support as possible, Head Start and Early Head Start programs are unable to serve the majority of eligible children and families. Head Start is serving only about half of eligible preschoolers and Early Head Start is serving less than three percent of babies and toddlers.

Infants and toddlers are more likely to live in poverty, and economists predict that this recession will be longer and more severe than any the United States has faced in recent decades, suggesting that many more families will need the comprehensive supports that Head Start and Early Head Start provide.

CLASP looks forward to working with the Committee to continue to reverse the losses in recent years and ensure that early childhood programs, including Head Start, Early Head Start, and the Federal Child Care Assistance Program, stay firmly on the growth path set out in the recent economic recovery package and the 2010 budget proposal from the Administration. These investments are vital components of economic recovery because they support the important early years of a child's development, and that is critical to our Nation's future success.

Thank you.

Mr. OBEY. Thank you very much. Appreciate your time.

[The information follows:]



**CLASP**  
CENTER FOR LAW AND SOCIAL POLICY

Testimony of Danielle Ewen  
Director, Child Care and Early Education  
Center for Law and Social Policy  
Washington, DC  
Before the Committee on Appropriations  
Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies  
U.S. House of Representatives  
March 18, 2009  
10:00 am

Testimony Summary:

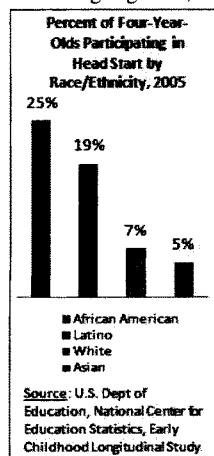
Ms. Ewen will testify about the importance of growing federal investments in Head Start and Early Head Start, part of the Administration for Children and Families in the Department of Health and Human Services, in order to support our most vulnerable infants, toddlers, preschoolers, and their families.

Testimony of Danielle Ewen  
Before the Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies  
U.S. House of Representatives  
March 18, 2009

Chairman Obey, members of the Subcommittee, thank you for the opportunity to testify about the importance of growing federal investments in Head Start and Early Head Start in order to support our most vulnerable infants, toddlers, preschoolers, and their families. Your support for these programs has long been critical to their success.

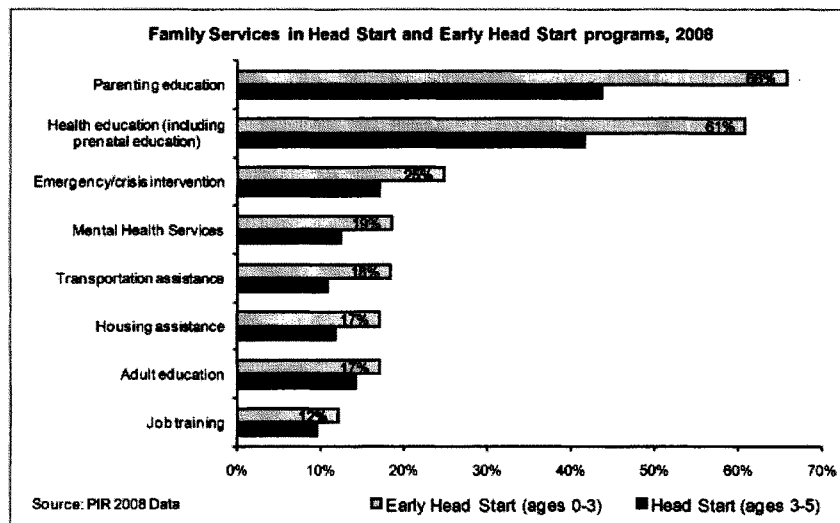
I am testifying today on behalf of the Center for Law and Social Policy (CLASP). CLASP is a national nonprofit that works to improve the lives of low-income people. CLASP's mission is to improve the economic security, educational and workforce prospects, and family stability of low-income parents, children, and youth and to secure equal justice for all. To carry out this mission, CLASP conducts research, provides policy analysis, advocates at the federal and state levels, and offers information and technical assistance on a range of family policy and equal justice issues for our audience of federal, state, and local policymakers; advocates; researchers; and the media.

As you know, Head Start and Early Head Start are the only federally funded programs providing comprehensive early education and support services for poor children and their families. Head Start programs provide services focused on the "whole child," including early education addressing cognitive, developmental, and socio-emotional needs; medical and dental screenings and referrals; nutritional services; parental involvement activities; and referrals to social service providers for the entire family. Both Head Start and Early Head Start have proven their effectiveness in national studies; more importantly, both programs have proven their effectiveness by improving the lives of children and families.



Head Start and Early Head Start serve a diverse array of children and families living in poverty. Seventy-seven percent of participants across all Head Start funded programs (including children participating in Head Start, Early Head Start, American Indian/Alaskan Native, and Migrant and Seasonal programs) are in families earning below the federal poverty level; another fifteen percent qualify because they receive public assistance.<sup>1</sup> Yet Head Start and Early Head Start families are working hard to become self-sufficient: 70 percent of all Head Start families include at least one working parent, and 13 percent of families include a parent in school or job training. Sixty-six percent of Early Head Start families have at least one employed parent, and 22 percent have at least one parent in school or job training. A greater proportion of African-American and Latino children participate in Head Start than do White or Asian children.<sup>2</sup>

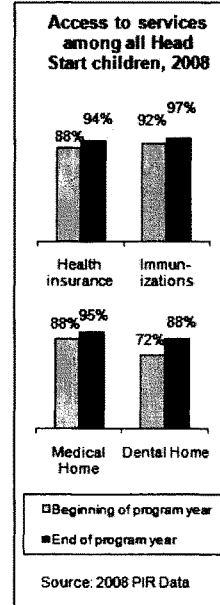
Children living in poverty face many risk factors to healthy development. Low-income children need comprehensive health and developmental services to identify and treat conditions that negatively affect their growth and development. Recognizing this, a core part of the Head Start/Early Head Start model is that programs must identify and meet these needs. For example, federal Head Start Program Performance Standards require that children attending Head Start and Early Head Start receive a comprehensive screening within 45 days of entering the program. Head Start and Early Head Start grantees must work with parents to determine that each child has an ongoing source of continuous, accessible health care, and is up-to-date on appropriate care and services within 90 days. If health and/or developmental concerns are identified, Head Start and Early Head Start staff members work to coordinate follow-up, treatment, and ongoing care for the children. The majority of families participating in Head Start programs receive services or referrals through Head Start; 84 percent of families in Early Head Start families and 73 percent of families in Head Start for preschool-age children accessed at least one service in 2008.



And this approach works. Head Start and Early Head Start promote better health for young children. Among children without health insurance at entry into Early Head Start, 55 percent obtained insurance during the program year. In 2008, 94 percent of children in the Early Head Start program had received all immunizations appropriate for their age (or all immunizations possible at the time) by the end of the program year—higher than national averages. According to the Centers for Disease Control and Prevention, 80 percent of all young children nationwide (ages 19-35 months) had received their recommended vaccination series in 2008. Among young children living in poverty, only 75 percent had received their recommended immunizations.<sup>3</sup>

Head Start and Early Head Start programs routinely screen children for developmental and physical delays and provide them with the services they need. In 2008, half of all children in Head Start with disabilities were diagnosed during the program year; without the intervention of the program, it is likely that these issues would have gone undetected until children entered kindergarten or even first grade, putting them further behind their peers.

Research has demonstrated that children in Head Start and Early Head Start benefit from the program in other ways as well. The Family and Child Experiences Survey (FACES) demonstrated that children who have participated in Head Start are close to national norms in early reading, writing, and math skills after kindergarten.<sup>4</sup> Early Head Start has also been positively evaluated, with researchers reporting that: 2-year-old children with at least one year of Early Head Start performed better on measures of cognitive, language, and socio-emotional development than their peers who did not participate, and children who attended Early Head Start continued to outperform children in the control group at age 3. Parents of Early Head Start children also performed better on measures of the home environment, parenting, and knowledge of child development. These parents were also more likely to participate in job training and education and to be employed, in comparison to families who did not participate in Early Head Start.<sup>5</sup>



These results are not surprising to the children and families who participate in Head Start and Early Head Start programs. The success of the programs is tied to a set of core beliefs that ensure that the needs of every child are met. Head Start providers are experts at forming community partnerships, engaging in coordination, and reaching out to new and diverse allies in their community. They also recognize the need for continual improvement.

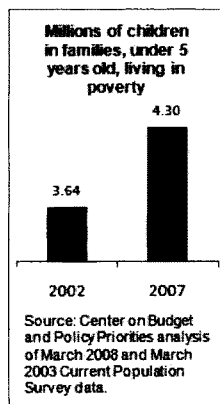
As a result, across the country, Head Start programs are partnering with state pre-kindergarten programs to provide high-quality full-day experiences for the children in the state programs. In Hamilton County Schools in Chattanooga, Tennessee, the school district uses Title I funds in conjunction with Head Start funds to expand the availability of high-quality classrooms. In these classrooms, Head Start funds ensure that the Performance Standards are met for the time children are in the program and Title I supports the instruction of a bachelor degreed teacher for the 6.5 hour day.

In Birmingham, Alabama, the Head Start agency has taken another approach to partnerships. Recognizing that children are in a variety of settings when working families need full-day and -year child care, the agency has partnered with family child care providers to provide Head Start services in family child care homes. Child care providers are trained in the Head Start model and receive the full range of professional development and other supports; providers meet all of the Performance Standards for each child and are monitored on a regular basis.

Head Start and Early Head Start also partner with the child care subsidy program to help families access full-day and -year settings, but state shortfalls in funding for child care assistance means that parents of children who participate in Head Start and Early Head Start often cannot get help paying for child care for the rest of the day. Programs, or individual families, must turn to multiple funding sources to piece together a full-day, comprehensive program that meets the needs of working families. Yet, insufficient funding for the Child Care and Development Block Grant (CCDBG) limits the ability of many Head Start and Early Head Start programs and families to do so and ensure that the full range of children's and families' needs are met.

Programs are also working to improve the quality of the services they provide to children and families, building on the reauthorization of the Head Start program in 2007:

- Among Head Start teachers serving preschool-age children, 80 percent had at least an Associate's Degree (A.A.) in early childhood education or a related field in 2008. In addition, 42 percent of teachers had a Bachelor's Degree (B.A.) or higher in early childhood education or a related field.
- Among Early Head Start teachers serving infants and toddlers, 54 percent had at least an A.A. in early childhood education or a related field in 2008. In addition, 25 percent of teachers had a B.A. or higher in early childhood education or a related field.
- Among Early Head Start teachers without a degree in 2008, many had a credential or were pursuing a degree program. Thirty-two percent of teachers had a C.D.A. or state equivalent and of these teachers, 34 percent were in a degree program. Among teachers without a degree or C.D.A., 60 percent were in a degree program or C.D.A. training.
- Teacher qualifications have increased dramatically in recent years. Across all types of Head Start programs, in 2001, only 41 percent of teachers had at least an A.A., and only 22 percent of teachers had a B.A. or higher in early childhood education or a related field. In 2008, across all types of Head Start programs, 75 percent of teachers had at least an A.A., and 41 percent of teachers had a B.A. or higher in early childhood education or a related field.



Even as they leverage as much support as possible for vulnerable children and families, Head Start and Early Head Start programs are unable to serve the majority of eligible children and families. Recent estimates suggest that Head Start is serving only about half of eligible preschool-age children, and less than 3 percent of babies and toddlers who are eligible for Early Head Start are reached at current federal funding levels.<sup>6</sup> Infants and toddlers are more likely to live in poverty than older children, and recent data suggests that the percentage of children living in poverty is increasing. Economists predict that this recession will be longer and more severe than any the United States has faced in recent decades,<sup>7</sup> which means that many more families will need Head Start and Early Head Start services. Many of these families live in poor communities with a only handful of pediatricians, dentists, or health clinics; limited access to job training and other supports; and few high-quality early childhood programs, making the

Head Start and Early Head Start services even more important. Unfortunately, appropriations for these programs have not been keeping pace with growing need.

The comprehensive approach that Head Start and Early Head Start take is currently available to only a limited number of families. Federal funding has been limited in recent years, and programs have had to make dramatic cuts in the number of children served, in the hours they are available, and in the services they provide. Programs have had to limit meals, provide powdered milk instead of more expensive real milk, stop transporting children to doctors and dentists, and cut other critical support services.

CLASP looks forward to working with the Committee to continue to reverse these cuts and ensure that early childhood programs, including Head Start, Early Head Start, and CCDBG, stay firmly on the growth path that the Administration set out in the recent economic recovery package and their 2010 budget proposal. These investments are vital components of economic recovery, because they invest in the critical early years of a child's development, which is an investment in our nation's future.

Growth in Head Start and Early Head Start is necessary in FY 2010 to enable these programs to continue to meet the needs of the young children and their families that they serve as well as reach the growing number of unserved children who could benefit from a comprehensive early learning experience.

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<sup>1</sup> Data throughout this testimony is from the 2008 Head Start Program Information Reports (PIR) if not otherwise noted.

<sup>2</sup> U.S. Department of Education, National Center for Education Statistics, Early Childhood Longitudinal Study, Birth Cohort.

<sup>3</sup> Centers for Disease Control and Prevention, "Vaccines & Immunizations, Statistics and Surveillance: July 2007-June 2008 Table Data," [http://www.cdc.gov/vaccines/stats-surv/nis/data/tables\\_0708.htm](http://www.cdc.gov/vaccines/stats-surv/nis/data/tables_0708.htm). The reported recommended vaccination rates are for the five vaccine series known as the 4:3:1:3:3 combined series.

<sup>4</sup> Nicholas Zill and Alberto Sorongon, Children's Cognitive Gains during Head Start and Kindergarten, Presentation at the National Head Start Research Conference, Washington, DC, June 28-30, 2004.

<sup>5</sup> U.S. Department of Health and Human Services. *Making a Difference in the Lives of Infants and Toddlers and Their Families: The Impacts of Early Head Start*. 2002.

<sup>6</sup> Calculations by National Women's Law Center, based on Census data on children in poverty and Head Start Bureau data on children served by Head Start and Early Head Start, 2006.

<sup>7</sup> Jared Bernstein, *Testimony Before the House Committee on Ways and Means*, October 29, 2008. <http://waysandmeans.house.gov/hearings.asp?formmode=view&id=7463>

**DANIELLE EWEN**  
**Director, Child Care and Early Education Team**

Danielle Ewen is the Director of the Child Care and Early Education team at the Center for Law and Social Policy (CLASP). She works on federal and state issues around child care and early education, particularly the reauthorizations of the Child Care and Development Block Grant and Head Start. She has written extensively about financing high quality early care and education systems, as well as the federal child care subsidy program and how it impacts low-income families, and state and local policies to create and implement early childhood programs. She is the author and co-author of numerous publications on state and federal policy, including *All Together Now*, a research report that examines the implementation of state pre-kindergarten programs in community-based child care settings, several reports on the use of Title I funds for early childhood programs, and analyses of federal and state child care subsidy policies.

Prior to joining CLASP, Danielle Ewen worked at the Children's Defense Fund as a Senior Program Associate in the Child Care and Development Division. Ms. Ewen was also the Assistant Director for the National Child Care Information Center and worked as a Policy Analyst at the US Department of Education in the Office of Migrant Education, where she worked on issues related to implementation of Chapter 1 programs, family literacy, bilingual education and evaluation.

She holds a Bachelor's Degree from the University of California at Berkeley and a Master's in Public Administration from Columbia University. She lives and works in Washington, DC.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Danielle Ewen  
Center for Law and Social Policy  
1015 Fifteenth Street NW Suite 400  
Washington, DC 20003  
202-906-8004

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

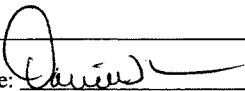
I represent the Center for Law and Social Policy.

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes

☒ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

Signature: 

Date: 3/7/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.



WEDNESDAY, MARCH 18, 2009.

**NATIONAL ASSOCIATION OF CHARTER SCHOOL  
AUTHORIZERS**

**WITNESS**

**GREG RICHMOND**

Mr. OBEY. Next, Mr. Greg Richmond, National Association of Charter School Authorizers.

I do not know if we should let any authorizers in the room.  
[Laughter.]

Mr. RICHMOND. Good morning, Chairman Obey, Ranking Member Tiahrt, members of the Subcommittee. My name is Greg Richmond and I am the President and Chief Executive Officer of the National Association of Charter School Authorizers, or NACSA. Thank you for the opportunity to testify before your Subcommittee on actions that the Federal Government can take to improve quality within the charter school sector.

NACSA is a trusted resource and innovative leader for charter school quality. We are a professional membership organization, but our members are not charter schools; our members are the agencies or the authorizers that oversee public schools on behalf of the public. We have many members and perform work in many of the cities and States that you represent on this Committee.

We know that a number of cities and States across the Country have many quality charter schools. Recent studies in Boston, New York, Chicago, New Orleans, and Oakland are showing that charter schools can raise test scores, graduate more students, and send more students to college.

But we also know that there is nothing easy or automatic about charter school quality, and that there are some places where there are too many weak charter schools. We support President Obama's call, stated last fall and again last week, for increasing the number of charter schools and for raising our standards for charter school quality.

Since 1995, the U.S. Department of Education has spent more than \$1,700,000,000 on its Federal Charter School Program, or CSP. While these funds have promoted the growth of the charter school sector, they have done less to promote consistent quality within that sector.

Currently, the CSP requires charter schools to meet very few requirements, such as admitting students via random lottery and following basic civil rights laws. Absent are critical standards and practices that would strengthen charter school operations and outcomes. Congress should take several small, but important, steps to put academic and financial quality controls in place within this important Federal program. These quality controls can be achieved through four steps: contracts, student performance requirements, audits, and proper monitoring.

First, contracts. The charters held by charter schools are multi-year, multi-million dollar arrangements under which schools provide education services in exchange for receiving public funds. Yet, by our estimate, between 10 and 20 percent of charter schools across the Nation do not operate under a basic legal contract. This

is unacceptable and the CSP should require all charter schools to operate under the terms of a legal contract.

Second, student performance requirements. Accountability is at the core of the charter school philosophy. Yet, too many low performing charter schools remain open because charter school accountability requirements in their State are vague and not centered on student performance. We need to close these low performing charter schools because they are not serving students well and because they are undermining those charter schools that are excelling. The Charter Schools Program should require that charter schools meet the same objective measurable student performance standards that apply to all other public schools in a State.

Third, audits. Some of the most troublesome problems in the charter school sector have occurred due to a lack of adequate financial controls at a small number of schools. Most States, but not all States, require charter schools to conduct annual independent, financial audits. The Federal Charter School Program should require all charter schools to do so.

Finally, monitoring. We know that passing new strong laws that incentivize quality is only the first step. Laws are of little value if no one is monitoring or enforcing them. The role of the authorizer is to provide that oversight on behalf of the public. To this end, Congress should require that a small portion of Federal Charter School Program funds be used to improve the quality of authorizing.

Since the program's inception, State education agencies have been allowed to use five percent of funds for their own general administration. In the future, a portion of these funds should be used to improve the practices of authorizers and thereby improve the quality of monitoring. Taken together, these small but important steps—contracts, student performance requirements, audits, and monitoring—will go a long way toward achieving the shared goal of President Obama and U.S. Secretary of Education Arne Duncan to promote, support, and strengthen the charter school sector.

I appreciate this opportunity to testify on the need for quality controls among charter schools and authorizers. By establishing these quality controls, we will take a strong step forward in our efforts to provide all of our students with the greatest educational opportunities possible. Thank you.

[The information follows:]

**Written Testimony of Greg Richmond  
President and Chief Executive Officer  
National Association of Charter School Authorizers (NACSA)**

**Before the House Committee on Appropriations Subcommittee on Labor, Health  
and Human Services, Education, and Related Agencies**

**Wednesday, March 18, 2009  
10 am**

**Subject: To amend the federal Charter School Program (CSP) to include critical  
“quality controls” - contracts, student performance requirements, audits, and  
proper monitoring - to strengthen charter school authorizing practices and provide  
our nation’s students with great educational opportunities.**

Chairman Obey, Ranking Member Tiahrt, Members of the Subcommittee, my name is Greg Richmond, and I am the President and Chief Executive Officer of the National Association of Charter School Authorizers (NACSA). Thank you for the opportunity to testify before your Subcommittee on actions that the federal government can take to improve quality within the charter school sector.

The National Association of Charter School Authorizers (NACSA) is the trusted resource and innovative leader for charter school quality. With nearly a decade of experience in cities and states across the country - from Chicago to Denver, from New Orleans to Oakland - NACSA is leading efforts to create and sustain high quality charter schools by providing training, consulting, and policy guidance to authorizers and education leaders.

Authorizers are the entities empowered by state charter school laws to approve, oversee, and evaluate charter schools. Across the country, state departments of education, school districts, institutions of higher learning, nonprofit organizations, and municipal offices are fulfilling this important role. When done thoughtfully, purposefully, and professionally, authorizing creates an innovative, public market space for autonomous, accountable public schools. Authorizers determine who can enter this new market space, how these schools will be permitted to operate, and which schools will be allowed to remain open and expand.

Just last week during an address to the US Hispanic Chamber of Commerce, President Obama addressed the need for strong authorizing, stating, “the expansion of charter schools must not result in the spread of mediocrity, but in the advancement of excellence. And that will require states adopting both a rigorous selection and review process to ensure that a charter school's autonomy is coupled with greater accountability – as well as a strategy, like the one in Chicago, to close charter schools that are not working.”

Since 1995, the US Department of Education has spent more than \$1.7B on its federal Charter School Program (CSP). While these funds have promoted the growth of the charter school sector, they have done less to promote consistent quality within that sector. In fact, the CSP has no quality controls related to school academic performance and has weak quality controls related to school operations and finance.

Currently, the CSP requires charter schools that receive CSP funds to meet very few requirements – such as admitting students via random lottery and following civil rights laws. Absent are critical standards and practices that would help to strengthen charter school quality. Congress should take several small but important steps to immediately put academic and financial quality controls in place within the federal program. These quality controls can be achieved through four steps: contracts, student performance requirements, audits, and proper monitoring.

1) Contracts - The “charters” held by charter schools are multi-year, multi-million dollar arrangements under which charter schools provide public education services in exchange for receiving public funds. These arrangements should be defined in a contract that details the rights and responsibilities of two parties: the school and its authorizer.

By our estimate, between 10% and 20% of charter schools across the nation do not have a contract that spells out either the school's or the authorizer's rights and responsibilities. In this day and age, it is inappropriate to distribute millions of dollars for public education without clear, transparent contracts. The lack of a contract makes it difficult for an authorizer to protect the public's interests and leaves the charter school vulnerable to over regulation.

The CSP should require charter schools in states that receive CSP grants to have a contract, executed by school and authorizer, which defines each party's rights and responsibilities. The contract should be for a defined term and should be considered a privilege, not a property right.

2) Student Performance Requirements - Accountability is at the core of the charter school philosophy. Charter schools that fail to meet high performance standards should be closed. Yet too many low-performing charter schools remain open because accountability standards in the charter sector are often too vague, subjective, and not centered on student performance.

This often occurs because most states first passed their charter school laws before the enactment of the No Child Left Behind (NCLB) Act in 2001. As a result, many states have vague statutory language that says charter schools should "make progress" toward achieving pupil performance standards identified in the school's charter application, rather than actually requiring charter schools to achieve those standards. The disconnect between the charter school statute and subsequent NCLB requirements causes confusion and uncertainty when poor performing charter schools come up for renewal. This confusion is often resolved by taking the legally safe route of keeping the school open.

The CSP should require that the states receiving CSP grants hold their charter schools to the same measurable student performance standards as other public schools in the state.

3) Audits and Public Information - Sound financial practices and systems are essential to maintain the viability of a charter school and to assure the public that its resources are being used appropriately. Some of the most troublesome problems in the charter sector have occurred due to a lack of adequate financial controls.

The CSP should require charter schools in states that receive CSP grants to annually retain a qualified, independent auditor to conduct an annual audit of the charter school's financial statements and practices and to file that audit with its authorizer. CSP recipients should be subject to the open meetings and freedom of information laws that apply to all public schools.

4) Proper Monitoring - Finally, we know that passing new, strong laws that incent quality is only the first step. Laws are of little value if no one is monitoring or enforcing them. The role of the charter school authorizer is to provide that oversight on behalf of the

public. To this end, Congress should require that a portion of CSP funds be used to improve the quality of authorizing.

Since the CSP's inception, state education agencies have been allowed to use 5% of their grant funds for their own administration. These funds have almost always been used by SEAs to balance the bottom line of their own operating budget. Instead, a portion of these funds should be used to improve the practices of authorizers.

The CSP should be amended to reallocate the 5% administrative funds as follows:

- (a) 1.5% of all federal charter funds should be retained nationally for authorizer improvement initiatives, which may include an authorizer certification pilot or enhanced data collection;
- (b) 2% of CSP funds should be used by SEAs to improve the quality of authorizing in their state, as set forth in each state's applications, for planning, training, and systems development; and
- (c) 1.5% of CSP funds should be retained by SEAS for administration to administer the program.

Taken together, these small but important steps - contracts, student performance requirements, audits, and proper monitoring - will go a long way towards achieving the shared goal of President Obama, US Secretary of Education Duncan, business leaders, civil rights advocates, and innovative educators to promote, support, and strengthen the charter school sector.

I appreciate this opportunity to testify on the need for quality controls among charter school authorizers. Too many students graduate from high school without the skills necessary to succeed in college or compete in the global marketplace, and some fail to complete high school at all.

By establishing quality controls within the charter school sector, we will take a strong step forward in our efforts to provide all of our students with the greatest educational opportunities possible. We should not accept anything less. We owe it to our children. Thank you.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:	
Greg Richmond National Association of Charter School Authorizers 105 West Adams, Suite 1430 Chicago, Illinois 60603 (312) 376-2300	
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.  National Association of Charter School Authroizers	
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?  <input checked="" type="radio"/> Yes      No	
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.  Amount:      \$362,505 Source:      US Department of Education Charter Schools Program – National Leadership Activities  Recipient:    NACSA was the sub-recipient of grant awarded to Colorado League of Charter Schools, Award No: U282N060030. Effective October 1, 2007, NACSA's status as a sub-recipient in the project was changed to vender/contractor.	

Signature: \_\_\_\_\_

Date: 3-18-09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you. Just a quick question. Do you happen to know how many charter schools we would find in a small town or rural area as opposed to how many we would find in your major metropolitan areas?

Mr. RICHMOND. More charter schools are in major metropolitan areas, but it does vary by State to State. Wisconsin has a pretty significant population of charter schools outside of major metropolitan areas relative to other States. Colorado also has more charter schools outside of major metropolitan areas. But in some States it is the opposite; they are concentrated in big cities. And that is a function of State laws and the role of school districts in supporting those schools.

Mr. OBEY. Thank you.

Mr. TIAHRT.

Mr. TIAHRT. Thank you, Mr. Chairman.

Mr. Richmond, you mentioned Chicago in your testimony. Are you familiar with Secretary Duncan?

Mr. RICHMOND. Yes, I know him well. I used to work with Arne at the Chicago Public Schools.

Mr. TIAHRT. And there are charter schools in Chicago. You mentioned in here that part of the plan was that if they were not working, you would close the charter schools. How would you measure that and how did you determine success or closure?

Mr. RICHMOND. We put forward some very straightforward measurements: not only test scores, but also attendance, graduation rates, and then we did look at finances to make sure the finances were being properly managed, and we audited those every year.

But we defined very clear measurable outcomes. In each school we had a contract; with each school, we signed it, they signed it, and said these are the performance expectations. If you achieve these you will be renewed, you will stay open; if you do not achieve them, you are at risk of being closed. During my time there, we closed two schools.

Mr. TIAHRT. Out of how many?

Mr. RICHMOND. Out of about 30.

Mr. TIAHRT. Interesting. Thank you, Mr. Richmond.

Mr. JACKSON. Mr. Chairman?

Mr. OBEY. Thank you.

Mr. JACKSON. Very quickly.

The President said, in his most recent address to Congress, that we cannot be a Nation—if I remember correctly—that is satisfied with just graduating students from high school, and that someone who is dropping out of school is not just dropping out on themselves, they are also dropping out on every citizen and on the society.

Has your association ever thought about adding the college acceptance rates as a criteria to the effectiveness of the charter school? Not that you are just graduating students from high school, but that they are being accepted to college; that they are attending college; and that they have a low matriculation out of the institution as one of the criteria?

Mr. RICHMOND. We are actually working on that as we speak in a joint project with ourselves, the National Alliance for Public Charter Schools, and a center at Stanford University, where we are



putting forward, with Federal support, a broader set of school quality measures that include test scores, but then also include tracking how many students go on to college.

This was a very important lesson that we learned in Chicago that came out of the charter sector. There was a school on the west side in North Lawndale, in the late 1990s, that was doing a fantastic job preparing kids to go to college, actually helping them apply and make sure they got in.

Nothing like that had been happening in the regular city high schools. Arne Duncan saw that happening at the charter school on the West Side, he hired that gentleman from the charter school to come into the central office of the school district and put that in place for all high schools in the city. It is tremendously important that all kids have the opportunity to go on to college.

Mr. OBEY. Thank you.

Ms. LEE. Question.

Mr. OBEY. Go ahead.

Ms. LEE. Good morning.

Mr. RICHMOND. Good morning.

Ms. LEE. Thank you, Mr. Chairman. Let me just ask a quick question about the distinction between public charter schools and private charter schools. I have been one who has been very skeptical of charter schools, and I am trying to hear a compelling case to make my mind up whether I support or do not support charter schools, because I have seen evidence both ways.

Mr. RICHMOND. Right. Except in Arizona, where they do have something that is called private charter schools—and I honestly do not even know what they are—everywhere else in the country, all charter schools are public schools and, to me, the thing that makes them public is the fact that they are publicly funded, they are publicly monitored—they are accountable for finances and test scores—and they are open to all students, they serve students on behalf of the public. Those are the things, to me, that make them public schools, because they have the funding, the monitoring, and the service to all students. They cannot discriminate, they cannot administer tests. They have to be open to all.

Mr. OBEY. Mr. Cole.

Mr. COLE. Thank you, Mr. Chairman.

It is my understanding, Mr. Richmond, that, in the wake of Hurricane Katrina, your organization did a lot to get charter schools up and operational in New Orleans. Obviously, you have got a pretty concentrated experience there, and experiment. I am just curious what your observations are, what role they played, how successful they have been.

Mr. RICHMOND. I think that the work has been very successful. It certainly is not something we have done alone, but I traveled to Louisiana shortly after Hurricane Katrina, first met with State Superintendent Cecil Picard. I now work closely with State Superintendent Paul Pastorek. Every charter school that has opened in New Orleans since the hurricane, our association has evaluated on behalf of the State of Louisiana and made those recommendations.

But it is not just us. The real strength of this is that New Orleans public education before the hurricane was really almost a lifeless system. There was no hope in the city that anyone could fix

what was happening in the traditional school district. Afterwards, by opening up so many charter schools has really created a lot of opportunity. There is a much greater level of engagement: community engagement in schools, parent engagement in schools, teacher engagement. Much greater optimism.

And the real importance of that, when all is said and done, the charter schools that have opened in New Orleans since the hurricane are performing 50 percent higher on the State's academic performance system than the schools that the State opened at the same time. Same kids; same neighborhoods; anyone can go to either school. The charter schools are performing 50 percent higher than the traditional schools opened by the State.

Mr. OBEY. Thank you.

Mr. RICHMOND. Thank you.

Mr. OBEY. Let me simply observe that I hope people understand that just because members on the Committee do not ask questions of most witnesses, that is not because of a lack of interest; we are trying to stifle ourselves so that as many people have an opportunity to talk here today as possible. Something about Mr. Richmond's testimony or else the subject matter itself triggered an unusually long round of questions. So you ought to try to figure out what that was, because you certainly had everybody's interest.

Mr. RICHMOND. I am a native of Wisconsin, Mr. Chairman, so that has to be what it was.

Mr. OBEY. Aha. Well, I hope it is Northern Wisconsin.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL ASSOCIATION OF STATE DIRECTORS OF  
SPECIAL EDUCATION**

**WITNESS**

**MARY WATSON**

Mr. OBEY. Okay, next, Helen Blank, National Women's Law Center.

Oh, I am sorry, I got ahead of myself. First it is National Association of State Directors of Special Education, Mary Watson. Sorry about that.

Ms. WATSON. Good morning, Mr. Chairman and members of the Committee. My name is Mary Watson, Director of Exceptional Children Division for the Department of Public Instruction for the State of North Carolina. I am speaking to you today as President of the Board of Directors for the National Association of State Directors of Special Education. NASDSE is the national not-for-profit association that represents State directors of special education. I thank you sincerely on behalf of NASDSE for the opportunity to appear before you this morning to talk about funding for special education programs under the Individuals with Disabilities Education Act, known as IDEA.

Mr. Chairman and members of the Committee, I first want to thank you sincerely for including support for special education in the American Recovery and Reinvestment Act. In North Carolina,

this came at a critical time, when services for students with disabilities were about to be suspended or teachers laid off.

While these funds are going to help States in the short term, for the next two years, we remain concerned about the long-term funding for IDEA. Even with the national budget crisis, no child with a disability can be turned away from our public schools.

My testimony will briefly address four parts of IDEA and funding for each of these parts.

The first is the Part B program, which serves children ages 3 through 21. When IDEA was reauthorized in 2004, the authorizers spoke about putting IDEA on a glide path to full funding. We ask you to appropriate funding for Part B for the fiscal year 2010 that will bring it closer to the full funding.

Section 619, a program that serves children ages 3 to 5. President Obama and Secretary Duncan have made pre-K programs one of their educational priorities. Section 619 was level-funded in fiscal year 2009, which represents a funding cut due to the across-the-board spending cuts in fiscal year 2008 appropriations. We urge you to provide a 10 percent funding increase for the Section 619 program.

The Part C program serves infants and toddlers from birth to age two. We have compelling evidence that indicates if services are received early on, they can help mitigate the services required at a later date, thus reducing costs of special education when children enter school. It is important that these children be identified and services be provided as soon as possible. While this Committee has increased funding slightly for Part C in fiscal year 2009, we request the Committee again consider increasing fund for the Part C program in recognition of the importance of identifying and meeting the needs of this young and vulnerable population.

The Part D program, the fourth part, provides valuable support to State education agencies and through State education agencies to the local education agencies. NASDSE would like to thank this Committee for increasing funding for several of the Part D programs in the fiscal year 2009 Omnibus bill. I would especially like to mention two of the programs of critical importance.

The Regional Resource Centers that are funded through the technical assistance and dissemination line item in Part D is the first. These centers, over the years, have provided invaluable, hands-on support to States.

The State Personnel Development Grants, known as the SPDGs. From my own personal experience, I thank you for restoring the SPDGs in the fiscal year 2009 Omnibus bill that President Obama has just signed into law. This program is critical to supporting the personnel programs and special education which caused increased outcomes for students with disabilities.

In North Carolina, because of the professional development that was made possible through this funding, students with disabilities have more than double the progress made by their non-disabled peers in reading. For students with disabilities who were taught math by teachers who were trained using the SPDG funding, these students increased 27 percentage points, while regular education students only increased 3 percentage points. With respect to discipline of schools implementing positive behavior supports, office

discipline referrals have decreased, increasing instructional time, thus increasing achievement scores.

Across the States, the SPDG funding is used in various ways. In sum, this funding remains critically important to States and to students. NASDSE requests that you return this program to its original funding level by adding just \$2,000,000 and provide a 10 percent increase for the other Part D programs.

Mr. Chairman, this concludes my testimony. I would be happy to answer any questions. Thank you.

[The information follows:]

MARY WATSON

Director, Exception Children Division,  
North Carolina Department of Public Instruction and

President

National Association of State Directors

Of Special Education (NASDSE)

Alexandria, Virginia

Hearing of the

House Appropriations Subcommittee on Labor, Health and

Human Services, Education and Related

Agencies

March 18, 2009

10:00 a.m.

This testimony describes the individual components of the Individuals with Disabilities Education Act (IDEA) and addresses the need for increasing the appropriations for each component for FY 10.

Mr. Chairman and Members of the Committee:

My name is Mary Watson, Director of the Exceptional Children Division for the Department of Public Instruction for the State of North Carolina. I am here in my capacity as the President of the Board of Directors of the National Association of State Directors of Special Education. NASDSE is the national not-for-profit association that has represented the state directors of special education in the states, federal territories, the Department of Defense, the Bureau of Indian Education and the Freely Associated States since 1938. I thank you on behalf of NASDSE for the opportunity to appear before you this morning to talk about funding for special education programs under the Individuals with Disabilities Education Act (IDEA).

Mr. Chairman and Members of the Committee, I first want to thank you for including support for special education in the American Recovery and Reinvestment Act (ARRA). The \$12.2 billion targeted specifically for IDEA and the option to use the State Fiscal Stabilization Funds for special education will support some of the critical initiatives that are producing positive outcomes for students with disabilities that states are trying to implement and scale-up, but have lacked the fiscal resources with which to do so.

While the ARRA funds will help states in the short term, our members and their local special education colleagues remain concerned about the long term funding picture for IDEA. As you know, funding for IDEA is broken out into four broad categories: the Part B grants to states; the Section 619 pre-school program; the Part C infant/toddler

program and the Part D technical assistance program. My testimony will briefly address funding for each of these programs.

**Part B Grants to States.** The Part B program, which serves children with disabilities ages 3-21, is the largest component of IDEA and as such, it gets the most attention from this Committee, which has continued to provide incremental increases over the past few years as well as the ARRA funding that has literally doubled funding for the Part B program. Unfortunately, the huge increase provided by the ARRA will only last for two years. Half of the students with disabilities will not go away in FY 10 or FY 11 after the ARRA funds are gone and that is why it is so important that you continue your commitment to significantly increase funding for the Part B program in FY 10. We note that when IDEA was reauthorized in 2004, the authorizers spoke about putting IDEA on a 'glide path' to full funding. Unfortunately, we are not close to those glide path numbers even as we are nearing the reauthorization date for the IDEA. We urge the Committee to appropriate funding for Part B for FY 10 that will bring it closer to the goal of full funding. To move towards this goal, we ask for an appropriations level of \$15.7 billion.

**Section 619.** The Section 619 program, which serves children ages 3-5, received \$400 million in funding in the ARRA, but as is true for the Part B funding, these are short term funds that will only last for two years. Funding for Section 619 has either stagnated or been cut over the past few years. President Obama has noted the importance of pre-K programs in improving educational outcomes for all children and Secretary Duncan has listed improving and expanding pre-K programs as one of his priorities. To ensure that all children get off to a good start and come to school ready to learn, we believe that it is

critically important that children with disabilities have this same access to high quality pre-K programs that are specifically designed to support their individual needs. We note that Section 619 was level funded in FY 09, which represents a cut in funding due to the across-the-board spending cuts in the FY 08 appropriations. We therefore urge you to provide a 10% funding increase for the Section 619 program, which would raise funding for the program to \$412 million.

**Part C.** The Part C program, which serves infants and toddlers from birth through age 2, received \$500 million in the ARRA and in contrast to the 619 program, has seen modest increases in funding over the past few years. There is compelling evidence that indicates that if services are received early on, they can help to mitigate the services required at a later date, thus reducing the costs of special education when children enter school. But it is not just for this reason that we urge an increase in funding for this program. When infants and toddlers are identified at such a young age, their disabilities tend to be more severe and their parents may need help in learning to care for them. It is important that these children be identified and that services be provided as soon as possible. While this Committee increased funding slightly for the Part C program in FY 09, we request that the Committee consider increasing funding for the Part C program to \$482 million for FY 10 in recognition of the importance of identifying and meeting the needs of this young and vulnerable population.

**Part D.** The Part D programs provide invaluable support to the state education agencies and through them to the local education agencies. I would like to specially mention two programs of critical importance to the state directors:



- The **Regional Resource Center programs** that are funded through the technical assistance and dissemination (TA&D) line item in Part D. These centers over the years have provided invaluable 'hands on' support to the states, including on-site support, document review, assistance with preparation for monitoring visits and specific targeted assistance. Not enough can be said about the value of their partnership with the state directors of special education.
- The **State Personnel Development Grants (SPDGs)**. From my own personal experience, I want to thank you for restoring funding for the SPDGs in the FY 09 Omnibus bill that President Obama just signed into law. The support that the state directors have through the U.S. Department of Education's Office of Special Education Program's SPDG program is critical to supporting personnel programs in special education throughout the country.
  - Across the states, SPDG funding is used for a variety of purposes. Just to give you a feeling for how SPDG funds are used: Forty-one states use their funds for differentiating instruction; 35 for induction and mentoring; 23 for leadership development; 35 for professional development; 27 for progress monitoring; 36 for reading/literacy; 38 for scaling up best practices; 37 for family engagement; 26 for early childhood; 12 for low-incidence disabilities, including autism. The Department of Education maintains a website, [www.signetwork.org](http://www.signetwork.org), where you can find a chart that depicts how SPDG funds are being used in all the states.
  - In the remaining minute that I have, I'd like to share some data from North Carolina's SPDG or State Improvement Grant (SIG education programs).

Because of the professional development that was made possible with the SPDG funding, students with disabilities more than doubled the progress made by their nondisabled peers in reading over a five-year period.

Students with disabilities who were taught math by teachers trained with the SPDG funding increased by 27 percentage points as compared with three percentage points for other students. With respect to discipline, of schools implementing positive behavior supports using SPDG funds, office discipline referrals decreased significantly.

- o In sum, the SPDG remains a critically important program for the states. NASDSE requests that you return the SPDG program to its original funding level of \$50 million.

Mr. Chairman, this concludes my formal testimony. I thank you on behalf of NASDSE for the opportunity to appear before you this morning to talk about funding for special education programs. I would be happy to answer any questions that you or members of the Committee may have.

Mary N. Watson  
Director  
Exceptional Children Division  
North Carolina Department of Public Instruction

Mary Watson is the Director of the Exceptional Children Division with the North Carolina Department of Public Instruction. Prior to her current position, Mary served as Section Chief for the Policy, Monitoring and Audit Section of the Exceptional Children Division. She began her career in the North Carolina public school system in 1972 following graduation from Appalachian State University with a bachelor's degree in Elementary Education. She went on to complete Masters degree programs in Elementary Education, Exceptional Children and Administration. Mary has teaching experience in the areas of preschool, elementary and middle schools regular and special education and adult education. She has also worked as the Title VI B grant administrator for the State of North Carolina, a compliance consultant and as a regional consultant for special education. Mary has a passion for children and is dedicated to the provision of quality educational experiences for all children.

Mary and her husband, Ed, live in Raleigh, North Carolina. They have two grown children.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

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Your Name, Business Address, and Telephone Number:

Mary N. Watson  
301 N. Wilmington St  
P.O. Box 6356 Mail Service Center  
Raleigh NC 27699

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

*National Association of State Directors  
of Special Education*

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

*See Attached*

Signature: Mary N. Watson      Date: 3-18-09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**National Association of State Directors of Special Education  
Schedule of Expenditures of Federal Awards for  
the 15-month Period Ended September 30, 2008**

<b>Direct Grants:</b>	<b>Project Title</b>	<b>Grant Number</b>	<b>Federal Expenditures</b>
(1) U.S. Department of Education	State/Federal Information Administrative Information Exchange Program (Forum)	H326F0500 01	\$ 529,567
(2) U.S. Department of Education	The IDEA Partnership Project	H326A030 002	2,506,943
(3) U.S. Department of Education	The IDEA Partnership Project - Pass through	H326A030 002	299,303
(4) U.S. Department of Education	The National Coordination and Dissemination Center to Improve Strategies for the Recruitment & Retention of Qualified Personnel for Children with Disabilities	H326P030 002	754,760
(5) U.S. Department of Education	Charter Schools Unsolicited Grants (TA Customizer)	U282U030 007A	349,157
<b>Indirect Grants:</b>			
(1) U.S. Department of Education	Council of Chief State School Officers - Center for Teacher Quality (INTASC)	H325M020 001	41,820
(2) U.S. Department of Education	National Center Secondary Transition and Post School Outcomes	Unknown	12,417
(3) U.S. Department of Education	The Technical Assistance Center on Assessment (Outcomes)	H326G050 007	50,128

WEDNESDAY, MARCH 18, 2009.

**NATIONAL WOMEN'S LAW CENTER**

**WITNESS**

**HELEN BLANK**

Mr. OBEY. Now, we will hear from Helen Blank, National Women's Law Center.

Ms. BLANK. I am from Michigan. Not close enough, I guess.

Chairman Obey, members of the Subcommittee, thank you for the opportunity to testify. The National Women's Law Center works to increase low income women's access to Head Start, Early Head Start, and child care because they are all key to ensuring a family's economic security and their children's futures. We welcome your strong support for these programs.

Head Start was founded on one very common sense principle: children do not come in pieces. Helping children to exceed involves addressing the full array of factors that affect their development, most notably, the role that their parents play in their lives.

With its comprehensive approach to early childhood, Head Start and Early Head Start are fundamental building blocks of a high-quality early education system. Data is clear that low-income children such as those targeted by Head Start often start out at a disadvantage. Head Start is dedicated to these children who need the most intensive help. It offers them high-quality early education, as well as other supports. This comprehensive approach is not replicated in most other early education programs.

In Head Start, social workers help stressed families work through the challenges of unstable jobs, abusive relationships, and inadequate housing, as well as the depression and sense of hopelessness that comes from living on the edge. Health workers make sure children are screened and treated, and help parents navigate the community's health system, bringing children in rural areas to dentists that are miles away. Staff help parents become partners in their children's education. Programs collaborate with job training programs and local colleges to aid parents in gaining skills and returning to school. Fathers are helped to strengthen the connection they need with their children and their families.

What does this mean? A four-year-old boy came to an organ program quiet and withdrawn. The annual screening process identified him as hearing impaired and, after a referral to a local pediatrician and audiologist, he was found to be profoundly deaf. Through the efforts of Head Start staff, the child received intensive sign language education. Staff worked with the family, who only spoke Spanish, to access high-quality medical services. They also assisted the family in obtaining Cochlear implants for their son.

Head Start is also comprehensive in its approach to early learning, addressing language, math, literacy, science, as well as physical health, approaches to learning, social and emotional development, and creative arts.

Head Start is dynamic; it is constantly improving and updating its standards. The last reauthorization, which received strong bipartisan support, continued to strengthen the program with stronger standards in literacy and math, stronger requirements for teach-

ers, tougher accountability requirements for boards of directors, increased program reviews, a requirement for more programs to compete to renew their grants, increased requirements for collaboration with local school districts, and, very importantly, an increased focus on infants and toddlers.

Unfortunately, until the much welcomed increase for Head Start in the ARRA and the Omnibus bill, Head Start funding had been virtually flat since 2002. Instead of focusing on the goals of the reauthorization, programs had to make due with less: cutting the number of hours and days, reducing staff, cutting training, not replacing equipment or buying new books, reducing or eliminating transportation for children to the core program and to medical and dental appointment, threatening the poorest children's access to Head Start.

Programs have had less access to child care funds, making it more difficult to support full day services. The lack of child care funding is a significant challenge for Head Start parents and for countless others. That is why we are also grateful for the increase in CCDBG included in the ARRA and the Omnibus bill.

The funding included in the economic recovery legislation demonstrated a recognition that Head Start helps our economy today and in the future. We look forward to working with this Committee to ensure that Head Start, Early Head Start, and child care continue on the growth path the Administration has set out, because it underscores the importance of investing in the critical early years of a child's development.

It is essential, in fiscal year 2010, to enable these programs to continue to meet the needs of the low-income young children and families they serve, as well as reach the growing numbers of unserved children ages zero to five.

Thank you very much for all your support.

Mr. OBEY. Thank you.

[The information follows:]

Helen Blank

Director, Leadership and Public Policy, National Women's Law Center, Washington, DC 20036  
 Testimony Before the Subcommittee on Labor, Health and Human Services, Education and  
 Related Agencies on the Head Start Program in the Department of Health and Human Services,  
 March 18, 2009, 10:00 am.

Summary: The funding included for economic recovery demonstrated a recognition that Head Start and Early Head Start help our economy today—by employing teachers, directors, and support staff and offering job training and employment supports to parents—and helps our economy tomorrow—by giving children the skills and motivation they need to succeed. It made a down payment on the President's commitment to improving early childhood as the cornerstone of any education improvement effort.

Head Start and Early Head Start are exceedingly important because of the comprehensive supports they offer to the most disadvantaged low-income children. Head Start was founded a very common sense principle: children don't come in pieces. Helping children to succeed involves addressing the full array of factors that affect their development—most notably the role their parents play in their lives.

Children coming into Early Head Start and Head Start face many barriers. Nearly one-third of parents with children in Head Start have less than a high school diploma or GED.

Head Start offers these children high-quality early education as well as an extensive range of other supports. Head Start is comprehensive in its approach to early learning as well. Nearly four decades of research establish that Head Start improves the school readiness of young children. Despite the barriers they face, children—with the help of Head Start—catch up.

Head Start has a dynamic, constantly working to improve support to children. Program quality standards have been continually updated. Recognizing the importance of the earliest years, in 1993 Early Head Start was created. The 2007 reauthorization continued to strengthen the program by establishing stronger program standards in literacy and math, stronger requirements for teachers, tougher requirements for Head Start Boards of Directors, increased program accountability, a requirement for more programs to compete to renew their grants, increased requirements for collaboration with local school districts and an increased focus on infants and toddlers.

Until this year, Head Start's funding had been virtually flat since 2002. Programs were forced to make do with less while striving to give children and families what they need. Programs also have had less access to child care funds through Child Care and Development Block Grant, making it more difficult to combine Head Start and child care funding to support full-day services for families who need it.

We look forward to working with the Committee to ensure that Head Start and Early Head Start continue on the growth path that the Administration has set out in the ARRA because it underscores the importance of investing in the critical early years of a child's development. It is essential in FY 2010 to enable these programs to continue to meet the needs of the low-income young children and families that they serve, as well as reach the growing number of unserved children ages 0 to 5 who could benefit from a comprehensive early learning and care experience.





Testimony of Helen Blank, Director of Leadership and  
Public Policy at the National Women's Law Center

Before the Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies  
Hearing on

House Appropriations Committee  
U.S. House of Representatives  
March 18, 2009

Chairman Obey, members of the Subcommittee, thank you for the opportunity to testify about the importance of Head Start and Early Head Start to improving the futures of young children.

I am testifying today on behalf of the National Women's Law Center. The Center is a nonprofit organization that has worked since 1972 to advance and protect women's legal rights. The Center focuses on major policy areas of importance to women and their families. We work to increase low-income women's access to Head Start, Early Head Start, and child care because they are all key to ensuring these families' economic security and their children's futures.

I welcome the opportunity to speak to you today about Head Start and Early Head Start and your strong support for the programs most recently evidenced by the increased funding included in the ARRA and the Omnibus appropriations bill. The Center believes that Head Start and Early Head Start are exceedingly important and special programs because of the comprehensive supports they offer to the most disadvantaged low-income women and children. Head Start was founded on one very common sense principle: children don't come in pieces. Helping children to succeed involves addressing the full array of factors that affect their development—most notably the role their parents play in their lives. With their comprehensive approach to early childhood, Head Start and Early Head Start are fundamental building blocks of the high-quality early care and education system that the President aims to achieve.

Children coming into Early Head Start and Head Start face many barriers. The majority live in families with incomes below the federal poverty level. Nearly one-third of parents with children in Head Start have less than a high school diploma or GED.<sup>1</sup> Over one-quarter of children served in Head Start come from homes where English is not the primary language spoken at home.<sup>2</sup> Thirteen percent of Head Start children have a disability—most commonly a speech or language impairment.<sup>3</sup> Slightly over half of those children determined to have a disability are diagnosed after entering Head Start.<sup>4</sup>

Studies have demonstrated that low-income children such as those targeted by Head Start often start out at a disadvantage. Low-income children may have more limited vocabularies, be read to less often and live in homes with fewer books.<sup>5</sup> Without the strong start that they need prior to

entering kindergarten to set them on the path to success, low-income children often fall even further behind their peers once they are in school. For example, first-graders from non-poor families are more likely to recognize words by sight than first-graders from poor families and twice as many first-graders from non-poor families are proficient at understanding words in context, multiplication, and division as first-graders from poor families.<sup>6</sup>

Head Start is dedicated to the children who need the most intensive help, and it offers these children high-quality early education as well as an extensive range of other supports. This comprehensive approach is key to the program's success—and is not replicated in most other early education programs. In Head Start, social workers help stressed families work through the challenges of unstable jobs, abusive relationships, and inadequate housing, as well as the depression and sense of hopelessness that comes from living on the edge. Health workers make sure that children are screened and treated for their health problems and help parents navigate their community's health care system, finding hospitals that can offer life-saving treatment for their children or bringing children in rural areas to dentists that are miles away. Trained staff help parents become partners in their children's education. Programs collaborate with job-training programs at local colleges to aid parents in gaining skills and returning to school. Fathers are given opportunities to strengthen their connection with their children and their families.

What does this mean for a child or a parent in a Head Start program?

- In one rural area in Pennsylvania, pediatric dentists were rare. Head Start made several trips each year to Scranton, taking to the dentist children whose mouths need so much work that local dentists won't treat them. Parents didn't have the means to drive 180 miles, so the Head Start program arranged for their transportation.
- A four-year-old boy came to an Oregon program quiet and very withdrawn. Through the annual screening process, he was identified as hearing impaired, and after a referral to a local pediatrician and audiologist, was found to be profoundly deaf. Through the efforts of Head Start staff members, the child is currently receiving intensive sign language education and staff are working with the family, who only speaks Spanish, to access high-quality medical services. They are also assisting the family in obtaining cochlear implants for their son.
- In a Massachusetts program, a Bosnian family with limited English proficiency received extensive support through Head Start. With the mother not driving, the family support worker with Head Start took the family each week, sometimes by train to help the family become familiarized with the public transportation system, to their child's dental appointments at Tufts University. The Head Start program has helped the family to apply for and receive Food Stamps, and through Head Start, the mother participates in a weekly program designed to help non-English speakers learn basic English communication skills.

- In Washington state, Ellie was born six weeks premature, addicted to the heroine that her birth parents had used. At two, she was adopted by her aunt, who brought her to Head Start at age four. She had temper tantrums that lasted for two hours. While the program's teachers worked with Ellie on her pre-reading and math skills, Head Start social workers and nurses found Ellie and her aunt the counseling and other services they needed to help Ellie deal with abandonment and all the other issues she faced. Ellie became a successful elementary school student.

Head Start is comprehensive in its approach to early learning as well. Head Start standards address language, math, literacy, and science, as well as physical health, approaches to learning, social and emotional development, and creative arts. In many communities, Head Start and Early Head Start programs are the only early education program addressing this range of development and learning areas.

Nearly four decades of research establish that Head Start improves the school readiness of young children. Despite the barriers they face, poor children—with the help of Head Start—catch up. Head Start children, on average, enter the program below national norms on early literacy. After kindergarten, they are close to national norms in early reading, writing, and math skills, according to the Family and Child Experiences Survey.<sup>7</sup> The program narrows the gap between disadvantaged children and all children in vocabulary and writing skills. The Head Start Impact Study, a national random assignment study using data collected during the fall 2002-spring 2003 school year, found that the program had statistically significant impacts on cognitive, social, and emotional development, health, and parenting practices.<sup>8</sup>

Head Start has been a dynamic program, constantly working to improve services to children. For the past four decades, Head Start has incorporated child development research and worked to increase the quality of programs while expanding the number of children served. Program quality standards have been continually updated. With increasing evidence demonstrating that the earlier children and their parents are reached, the better their chance of success, Head Start responded. In 1993, recognizing the importance of the earliest years to a child's development, Early Head Start was created.

The last reauthorization in 2007, approved with broad bipartisan support, continued to strengthen the program through several measures, including:

- Stronger program standards in literacy and math.
- Stronger requirements for teachers and assistant teachers. The legislation requires all teachers to have an AA degree by 2011 and sets a goal that at least half of all teachers have a BA degree by 2013.
- Tougher accountability and transparency requirements for Head Start Boards of Directors.

- Increased program accountability. In addition to a comprehensive monitoring review every three years, programs will be subject to unannounced visits.
- A requirement for more programs to compete to renew their grants.
- Increased requirements for collaboration with local school districts.
- Increased focus on infants and toddlers. Recognizing the importance of the earliest years, half of all Head Start expansion funds are now targeted to Early Head Start. In addition, there are increased opportunities for programs serving preschool-age children to convert to serving infants and toddlers.

Unfortunately, until the much-welcome increase for Head Start and Early Head Start included in the ARRA and the increase in the recently passed Omnibus Appropriations bill, Head Start's funding had been virtually flat since 2002, making it challenging for programs to accomplish the goals of the reauthorization. Instead, programs were forced to make do with less while striving to give children and families what they need. Programs cut the number of hours and days they offered during the school year, eliminated summer hours, reduced staff, cut training, could not replace equipment or buy new books, and reduced or eliminated transportation for children to the core program as well as transportation to medical and dental appointments, threatening the poorest children's access to Head Start.

Head Start and Early Head Start programs also have had less access to child care funds with Child Care and Development Block Grant (CCDBG) discretionary funds frozen from 2002 until this year, making it more difficult to combine Head Start and child care funding to support full-day services for families who need it. Seventy percent of Head Start families have at least one working parent, and 14 percent include a parent in school or job training,<sup>9</sup> but many Head Start programs only operate on a part-day schedule. As a result, the lack of child care funds is a significant challenge for Head Start parents and for countless others. Only one in seven children eligible for federal child care assistance currently receive help.<sup>10</sup> That is why we are also grateful for the increase in CCDBG included in the ARRA.

With the current economy, more families than ever need the type of support that Head Start and Early Head Start offer. The funding included the economic recovery legislation demonstrated a recognition that Head Start helps our economy today—by employing teachers, directors, and support staff and offering job training and employment supports to parents—and helps our economy tomorrow—by giving children the skills and motivation they need to succeed. It made a significant down payment on the President's commitment to improving early childhood as the cornerstone of any education improvement effort. With increased support, Head Start can continue to strengthen its role in bolstering our economic well being now and in the future. We look forward to working with the Committee to ensure that Head Start and Early Head Start continue on the growth path that the Administration has set out in the ARRA because it underscores the importance of investing in the critical early years of a child's development. It is essential in FY 2010 to enable these programs to continue to effectively meet the needs of the low-income young children and families that they serve, as well as reach the growing number of

unserved children ages 0 to 5 who could benefit from a comprehensive early learning and care experience.

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<sup>1</sup> Katie Hamm, *More than Meets the Eye: Head Start Programs, Participants, Families, and Staff in 2005* (Washington, DC: Center for Law and Social Policy, 2006), 5, *available at* [http://www.clasp.org/publications/hs\\_brief8.pdf](http://www.clasp.org/publications/hs_brief8.pdf) (last visited Mar. 12, 2009).

<sup>2</sup> Center for Law and Social Policy, *Head Start Participants, Programs, Families, and Staff in 2006* (Washington, DC: Center for Law and Social Policy, 2008), 2, *available at* [http://www.clasp.org/publications/hs\\_pir\\_2006.pdf](http://www.clasp.org/publications/hs_pir_2006.pdf) (last visited Mar. 12, 2009).

<sup>3</sup> Hamm, 3.

<sup>4</sup> Hamm, 3.

<sup>5</sup> Betty Hart and Todd R. Risley, *Meaningful Differences in the Everyday Experience of Young Children* (Baltimore, MD: Paul H. Brookes Publishing Co., 1995); Federal Interagency Forum on Child and Family Statistics, *America's Children: Key National Indicators of Well-Being, 2008* (Washington, DC: U.S. Government Printing Office, 2008), Indicator ED1: Family Reading to Young Children, *available at* <http://www.childstats.gov/americaschildren/tables.asp> (last visited Mar. 12, 2009); Pamela High, Marita Hopmann, Linda LaGasse, Robert Sege, John Moran, Celeste Guterrez, and Samuel Becker, "Child Centered Literacy Orientation: A Form of Social Capital?" *Pediatrics*, 103 (4), 1999.

<sup>6</sup> Kristin Denton and Jerry West, *Children's Reading and Mathematics Achievement in Kindergarten and First Grade* (Washington, DC: National Center for Education Statistics, 2002), x.

<sup>7</sup> Nicholas Zill and Alberto Sorongon, *Children's Cognitive Gains during Head Start and Kindergarten*, Presentation at the National Head Start Research Conference, Washington, DC, June 28-30, 2004.

<sup>8</sup> U.S. Department of Health and Human Services, *Administration for Children and Families, Head Start Impact Study: First Year Findings* (Washington, DC: U.S. Department of Health and Human Services, 2005).

<sup>9</sup> Center for Law and Social Policy (2008), 2.

<sup>10</sup> Jennifer Mezey, Mark Greenberg, and Rachel Schumacher, *The Vast Majority of Federally-Eligible Children Did Not Receive Child Care Assistance in FY 2000* (Washington, DC: Center for Law and Social Policy, 2002), *available at* [www.clasp.org/publications/1in7full.pdf](http://www.clasp.org/publications/1in7full.pdf) (last visited Jan. 10, 2008).

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

<p>Your Name, Business Address, and Telephone Number:</p> <p>Helen Blank National Women's Law Center, 11 Dupont Circle, NW, Suite 800, Washington, DC 20001 (202) 319-3036</p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p>National Women's Law Center</p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?</p> <p>Yes      <input checked="" type="radio"/> No</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p>

Signature: Helen Blank      Date: March 16, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

*Curriculum Vitae***Helen Blank****Director of Leadership and Public Policy**

Helen Blank, as Director of Leadership and Public Policy at the National Women's Law Center, leads the Center's work on early education, as well as its leadership activities including PLAN, the Progressive Leadership and Advocacy Network, a program for emerging leaders on low-income women's issues.

Previously Ms. Blank served 24 years as the director of the Child Care and Development Division at the Children's Defense Fund. While at the Children's Defense Fund Ms. Blank spearheaded a variety of efforts for improved early learning legislation. In an effort to pass the Act for Better Child Care, the first comprehensive federal child care legislation, she organized the Alliance for Better Child Care. Additionally she developed a guide for the implementation of the legislation that was widely used by state policymakers and child care leaders. She was a principal figure in the development of Child Watch, a project in collaboration with the Association of Junior Leagues, which monitored the effects of the 1981 budget cutbacks on children and families. In 1991, she led an effective campaign to convince the Bush administration to issue regulations for a program that allowed states to use the new federal funds in the best interests of children. She was also a leader in efforts to expand and improve the child care provisions in welfare reform, subsequently developing a guide to assist states in implementing the provisions. In addition, she created the Child Care Now!® Campaign, an ongoing initiative, which attempts to focus attention on early care and education.

At CDF, she created and ran an emerging leaders program for rising leaders in early childhood education.

Prior to her work at the Children's Defense Fund, she spent two years at the Child Welfare League of America where she was instrumental in the development of child welfare reform legislation. Working with the National Child Nutrition Project, she directed a model food stamp outreach campaign in the Washington Metropolitan area that increased food stamp participation, and resulted in major improvements in the administration of the program in several local jurisdictions. In addition, she helped advocate for replication of this campaign in a number of states. She also developed an effort to create local hunger task forces.

Ms. Blank is a member of the T.E.A.C.H.® Early Childhood Advisory Committee, the board of Teach for America's Prekindergarten Initiative, the Child Care Food Program Sponsors' Forum, and the Advisory Board for LISC, the Local Initiative Support Corporation. Ms. Blank has a Bachelor's Degree from the University of Michigan and a Master's Degree in Urban Planning from Hunter College of the City University of New York.

WEDNESDAY, MARCH 18, 2009.

**UNITED TRIBES TECHNICAL COLLEGE**

**WITNESS**

**DAVID GIPP**

Mr. OBEY. Next we will hear from Dr. David Gipp, United Tribes Technical College.

Mr. GIPP. Thank you, Mr. Chairman. It is an honor to be here. I might say this is only the third time in the 35 years I have been in Indian education and education that I have been able to appear before this Committee, so it is a great honor to be here.

Mr. OBEY. Well, you have been lucky to avoid us so far.

[Laughter.]

Mr. GIPP. Thank you for having here, on behalf of our tribal communities. I am President of United Tribes Technical College, which has been around for about 40 years. We celebrate our fortieth anniversary this coming year here and we appreciate the opportunity.

I am going to get straight to the point and note our request, Mr. Chairman, and that is that we are requesting that the authorized programs under the Carl Perkins law, Section 117, that the amounts of \$8,500,000 or \$727,000 above the fiscal year 2009 enacted level be provided for principally two schools, United Tribes Technical College and Navaho Technical College, which benefit by this. Together, we serve close to 2,500 students and about 500 children on our campuses.

United Tribes is located in Bismarck, North Dakota, and we serve, as I mentioned, between 20 to 60 different tribes from throughout the region and throughout the Nation, along with 400 to 500 children on our campus, and we offer a comprehensive model that includes both early childhood centers, as well as a K through 8 elementary school that works principally with our adult population in 17 different areas of career and technical education. This is part of the benefit from the Carl Perkins law.

The second request that I will speak to is also providing for added funding under Title III and Title III-A of the Higher Education Act for the tribal colleges and universities, of which there are 37 throughout the United States, serving approximately 30,000 students throughout the United States of America. So we ask that those not only be reauthorized, but that the funds be provided for adequacy so that these institutions can continue in the development phases of their post-secondary programs, as well as needed construction facilities. All of these schools, with the exception of one or two, do not receive State appropriated dollars and they do not have the benefit of local tax bases, as is the case with United Tribes.

I mentioned, in the case of United Tribes, that we are a comprehensive model, and I mentioned some of the array of services that we provided. I will also highlight that we have about an 80 percent retention rate, a 94 percent job placement rate in the fields for which students graduate and go on, in many cases, to four-year institutions. We have a very good return on our investment and we have achieved our highest level of accreditation through the North



Central Association for Tenures. In 2011 we are up for our comprehensive, and we look forward to expanding our programs.

I should mention the need for providing these funds, and that is that about 51 percent of our population throughout Indian Country or where there are tribal populations is now under the age of 25, and, in many cases, 51 percent or more of that population is under the age of 18. We have a growing population. So the challenge is to meet the needs of this population in terms of education and training, so that is the role for us as we see it.

We will grow, in the case of United Tribes, from about an average of 1,100 students to about 5,000 students in the course of the next five years. That is how we look at it in terms of what is happening throughout our various communities. We offer courses that range from the licensed practical nursing, to criminal justice, to auto mechanics and the standard trades, to online education and five degrees that we provide therein.

So those are just some of the things that I mentioned, Mr. Chairman, and we would greatly appreciate the continuation of support of these institutions, given the fact that the previous Administration tried to zero us out this past year and Congress saw the wisdom of continuing the support of these very valuable institutions. Thank you.

Mr. OBEY. Thank you.

[The information follows:]

Witness: Dr. David M. Gipp  
President  
United Tribes Technical College  
Bismarck, North Dakota

Hearing: March 18, 2009  
10 a.m.

Representing: United Tribes Technical College

Testimony Summary:

- United Tribes Technical College is operated by the five Indian tribes in North Dakota, and has been providing education to Indian students from the Great Plains and around the nation for 40 years. We offer 17 two-year degree and 11 certificate programs.
- UTTC is fully accredited; has an 80% retention rate and a placement rate of 94 %.

Our appropriations requests are authorized in current law:

- \$8.5 million under Section 117 of the Perkins Act, Tribally Controlled Postsecondary Career and Technical Institutions. Perkins funds represent about half of our core funding. We do not have a tax base or state-appropriated funds on which to rely.
- Increased funding under Title III and III-A of the Higher Education Act (developing institutions) for facility construction. UTTC will be applying for funds for to help construct a technology and science building.

**UNITED TRIBES TECHNICAL COLLEGE**

3315 University Drive  
Bismarck, North Dakota 58504  
701-255-3285

Statement on  
FY 2010 Department of Education Carl Perkins Act Budget (Section 117) and HEA Title III

Submitted to  
House and Senate Appropriations Subcommittees on Labor-HHS-Education and Related Agencies

David M. Gipp, President, United Tribes Technical College (UTTC)  
Myra Pearson, UTTC Board Chairman and Chairman of the Spirit Lake Tribe

March 18, 2009

For 40 years, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished Indian students from throughout the nation. We are governed by the five tribes located wholly or in part in North Dakota. We have consistently had excellent results, placing Indian people in good jobs and reducing welfare rolls. The Perkins funds constitute about half of our operating budget and provide for our core instructional programs for many of our Associate of Applied Science degrees. We do not have a tax base or state-appropriated funds on which to rely.

The request of the United Tribes Technical College Board is for the following authorized programs:

- **\$8.5 million or \$ 727 thousand above the FY 2009 enacted level for Section 117 of the Carl Perkins Act.** These funds are shared via a formula by United Tribes Technical College and Navajo Technical College.
- **Provision of additional funding for Title III and Title III-A of the Higher Education Act (HEA) that provide construction funds for facilities at institutions of higher education (Title III) and at tribally controlled colleges (Title III-A).** For example, UTTC needs an additional \$10.9 million to complete the construction of a new science and technology building towards which UTTC already has obtained \$3 million.

The students who attend UTTC are from Indian reservations from throughout the nation, with a significant portion of them being from the Great Plains area. Our students come from impoverished backgrounds or broken families. They may be overcoming extremely difficult personal circumstances as single parents. They often lack the resources, both culturally and financially, to go to other mainstream institutions. Through a variety of sources, including funds from Section 117 of the Carl Perkins Act, UTTC provides a set of family and culturally-based campus services, including: an elementary school for the children of students, housing, day care, a health clinic, a wellness center, several on-campus job programs, student government, counseling, services relating to drug and alcohol abuse and job placement programs. The Carl Perkins funds we receive are essential to our students' success.

**Perkins Authorization.** Section 117 of the Carl D. Perkins Career and Technical Education Act (20 U.S.C. Section 2327) is the source of authorization of Perkins funding for UTTC. Section 117 is entitled “Tribally Controlled Postsecondary Career and Technical Institutions.” First authorized in 1991, Congress has continued this authorization in the subsequent reauthorizations of the Perkins Act. Funding under this Act has in recent years been distributed on a formula basis to UTTC and to Navajo Technical College.

Despite the explicit Congressional authorization for Carl Perkins funding for Section 117, and despite the Administration's requests for funding for Section 117 in all previous years, the Bush Administration requested nothing for this program for FY 2009. We are pleased that Congress recognized the value of UTTC's programs, and instead gave a priority to UTTC and Navajo Technical College by appropriating a \$227,000 increase for Section 117 Perkins in the recently enacted Omnibus Appropriations bill for FY 2009. However, in the process our Section 117 program was listed as an earmark, despite the authorization for the appropriated amount. As a continuing, authorized Native American serving program, we should not be considered an earmark.

**UTTC Performance Indicators.** United Tribes Technical College has:

- An 80 percent retention rate.
- A placement rate of 94 percent (job placement and going on to four-year institutions).
- A projected return on federal investment of 20-to-1 (2005 study comparing the projected earnings generated over a 28-year period of UTTC Associate of Applied Science and Bachelor degree graduates of June 2005 with the cost of educating them).
- The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable – ten years or until 2011- and with no stipulations. We are also one of only two tribal colleges accredited to offer accredited on-line (Internet based) associate degrees.
- More than 20 percent of our graduates go on to four-year or advanced degree institutions.

We also note the January 13, 2009, report of the Department of Education's Office of Vocational and Adult Education on its recent site visit to UTTC (October 7-9, 2008). While some suggestions for improvements were made, the Department commended UTTC in many areas: for efforts to improve student retention; the commitment to data-driven decision-making, including the implementation of the Jenzabar system throughout the institution; the breadth of course offerings; collaboration with four-year institutions; expansion of online degree programs; unqualified opinions on both financial statements and compliance in all major programs; being qualified as a low risk grantee; having no reportable conditions and no known questioned costs; clean audits; and use of the proposed measurement definitions in establishing institutional performance goals.

**The demand for our services is growing and we are serving more students.** For the 2008-2009 year we enrolled 1023 students (an unduplicated count), nearly four times the number served just six years ago. Most of our students are from the Great Plains, where the Indian reservations have a jobless rate of 76 percent (Source: 2003 BIA Labor Force Report), along with increasing populations. These statistics dramatically demonstrate the need for our services at increased levels for at least the next ten years.

In addition, we are serving 141 students during school year 2008-2009 in our Theodore Jamerson Elementary school and 202 children, birth to five, are being served in our child development centers.

**UTTC course offerings and partnerships with other educational institutions.** We offer 17 accredited vocational/technical programs that lead to 17 two-year degrees (Associate of Applied Science (AAS)) and eleven (11) one-year certificates, as well as a four year degree in elementary education in cooperation with Sinte Gleska University in South Dakota.

**Licensed Practical Nursing.** This program has one of the highest enrollments at UTTC and results in the greatest demand for our graduates. Our students have the ability to transfer their UTTC credits to the North Dakota higher educational system to pursue a four-year nursing degree.

**Medical Transcription and Coding Certificate Program.** This program provides training in transcribing medical records into properly coded digital documents. It is offered through the college's Exact Med Training program and is supported by Department of Labor funds.

**Tribal Environmental Science.** Our Tribal Environmental Science program is supported by a National Science Foundation Tribal College and Universities Program grant. This five-year project allows students to obtain a two-year AAS degree in Tribal Environmental Science.

**Community Health/Injury Prevention/Public Health.** Through our Community Health/Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population, the leading cause of death among Native Americans ages 1-44, and the third leading cause of death overall. This program has in the past been supported by the Indian Health Service, and is the only degree-granting Injury Prevention program in the nation. Given the overwhelming health needs of Native Americans, we continue to seek new resources to increase training opportunities for public health professionals.

**Online Education.** Our online education courses provide increased opportunities for education by providing web-based courses to American Indians at remote sites as well as to students on our campus. These courses provide needed scheduling flexibility, especially for students with young children. They allow students to access quality, tribally-focused education without leaving home or present employment. However, we also note the lack of on-line opportunities for Native Americans in both urban and rural settings, and encourage the Congress to devote more resources in this area.

We offer online fully accredited degree programs in the areas of Early Childhood Education, Community Health/Injury Prevention, Health Information Technology, Nutrition and Food Service and Elementary Education. Over 80 courses are currently offered online, including those in the Medical Transcription and Coding program. We presently have 50 online students in various courses and 137 online students in the Medical Transcription program.

We also provide an online Indian Country Environmental Hazard Assessment program, offered through the Environmental Protection Agency. This is a training course designed to help tribes understand how to mitigate environmental hazards in reservation communities.

**Computer Information Technology.** This program is at maximum student capacity because of limitations on resources for computer instruction. In order to keep up with student demand and the

latest technology, we need more classrooms, equipment and instructors. We provide all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

**Nutrition and Food Services.** UTTC helps meet the challenge of fighting diabetes and other health problems in Indian Country, such as cancer, through education and research. Indians and Alaska Natives have a disproportionately high rate of type 2 diabetes, and have a diabetes mortality rate that is three times higher than the general U.S. population. The increase in diabetes among Indians and Alaska Natives is most prevalent among young adults aged 25-34, with a 160 percent increase from 1990-2004. (Source: FY 2009 Indian Health Service Budget Justification). Our research about native foods is helping us learn how to reduce the high levels of diseases in our communities.

As a 1994 Tribal Land Grant institution, we offer a Nutrition and Food Services AAS degree in order to increase the number of Indians with expertise in nutrition and dietetics. Currently, there are very few Indian professionals in the country with training in these areas. Our degree places a strong emphasis on diabetes education, traditional food preparation, and food safety. We have also established the United Tribes Diabetes Education Center that assists local tribal communities, our students and staff to decrease the prevalence of diabetes by providing educational programs, training and materials. We publish and make available tribal food guides to our on-campus community and to tribes.

**Business Management/Tribal Management.** Another critical program for Indian country is business and tribal management. This program is designed to help tribal leaders be more effective administrators and entrepreneurs. As with all our programs, curriculum is constantly being updated.

**Job Training and Economic Development.** UTTC continues to provide economic development opportunities for many tribes. We are a designated Minority Business Development Center serving South and North Dakota. We administer a Workforce Investment Act program and an internship program with private employers in the region.

**South Campus Development.** The bulk of our current educational training and student housing is provided in 100 year old buildings, part of a former military base used by UTTC since its founding in 1969 and donated to us by the U.S. in 1973. They are expensive to maintain, do not meet modern construction and electrical code requirements, are mostly not ADA compliant, and cannot be retrofitted to be energy efficient.

As a result, UTTC has developed plans for serving more students in new facilities that will provide training and services to meet future needs. We are now developing land purchased with a donation that will become our south campus. Infrastructure for one-fourth of the new campus has been completed, and we have now obtained partial funds for a new, and badly needed, science, math and technology building. *We need an additional \$10.9 million to help complete this building.* Our vision for the south campus is to serve up to 5,000 students. We expect that funding for the project will come from federal, state, tribal and private sources. Without additional funding for Titles III and III-A of the Higher Education Act, that provide construction funds for campuses such as ours, many students will be denied the opportunity for higher education.

Our Department of Education funds are essential to the operation of our campus. Our programs at UTTC continue to be critical and relevant to the welfare of Indian people throughout the Great Plains region and beyond. Thank you for your consideration of our request.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

David M. Gipp, President  
United Tribes Technical College  
3315 University Drive  
Bismarck, ND 58504 – Tel. 701-255-3285 ext. 1218

**I am a governmental witness. United Tribes Technical College is operated by the five tribal governments of N.D. under a Indian Self-Determination and Education Assistance contract with the Bureau of Indian Affairs (Contract No. CTA90X35608) and is therefore considered a tribal organization. This is the practice of the Interior Appropriations Subcommittee which treats tribal organizations operating under the Indian Self-Determination law as tribal governments. President Gipp is testifying on behalf of the Tribal Governments that operate United Tribes Technical College.**

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

I am appearing on behalf of a governmental organization. See the above statement.

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

See the above statement.

Signature:



Date: March 13, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**David M. Gipp**  
United Tribes Technical College President

David M. Gipp is President of United Tribes Technical College, an intertribal, postsecondary technical college for American Indian students and their families in Bismarck, N.D. He was associated with the college during its founding by North Dakota tribal leaders between 1969 and 1972 and was named president of it on May 2, 1977.

Born in Fort Yates, ND, Gipp is an enrolled member of the Standing Rock Sioux Tribe. His Hunkpapa Lakota name is Wicahpi Isnala translates to Lone Star.

He earned an education at the University of North Dakota (1969) and holds a Doctorate in Laws, *Honoris Causa*, from North Dakota State University (1991) for his contributions in developing tribal higher education policy. He has been selected for numerous national and community awards.

His professional work since 1972 has been principally in the development of tribal colleges. He was instrumental in creating the first national legislation (1978) to assist tribally controlled community colleges. He has extensive background in vocational and higher education and has served on the U.S. Department of Labor Native American Employment and Training Council (1978-2005).

Among other posts, President Gipp is the past Executive Director (1973-1977) and President of the American Indian Higher Education Consortium (1978-1980, 1991-1993, 1999-2000, 2001-2003) and past Chair of the American Indian College Fund (2002, 2003-2004, 2005) and current Chair of the University of North Dakota INMED Advisory Council. He was the 1995 Indian Educator of the Year of the National Indian Education Association and 1997 North Dakota Multi Cultural Educator of the Year. Most recently he was named the Champion of Liberty by the ACLU of North Dakota (2008).

North Dakota Governor John Hoeven appointed him to the North Dakota Workforce Development Council, the North Dakota State Commission on National and Community Service and the North Dakota Quarter Design Selection Committee. He served on the Bismarck Mayor's Committee on Human Relations. He is a member of the Lewis & Clark Regional Development Council and numerous other boards.

President Gipp oversees all aspects of the college, which is accredited by the North Central Association of Colleges and Schools and offers 17 career/technical programs and 24 two-year degrees and on-year certificates.

\*\*\*\*\*

United Tribes Technical College, 3315 University Drive, Bismarck, ND 58504, [www.uttc.edu](http://www.uttc.edu)



WEDNESDAY, MARCH 18, 2009.

**ASSOCIATION OF UNIVERSITY CENTERS ON  
DISABILITIES**

**WITNESS**

**MICHAEL GAMEL-McCORMICK, PH.D.**

Mr. OBEY. Next, Dr. Michael Gamel-McCormick, Association of University Centers on Disabilities.

Mr. GAMEL-McCORMICK. Good morning, Chairman Obey, Ranking Member Tiahrt, and members of the Subcommittee. Thank you for the opportunity to testify today regarding fiscal year 2010 appropriations. My name is Michael Gamel-McCormick. I am the President of the Association of University Centers on Disabilities and the Interim Dean of the College of Human Services, Education and Public Policy at the University of Delaware.

I want to talk to you about two of our programs today, the University Centers for Excellence in Developmental Disabilities, what we sometimes call UCEDDs, and our Leadership Education in Neurodevelopmental and Related Disabilities, or LEND, Programs.

The mission of the UCEDDs is to advance policy and practices for and with people with developmental and other disabilities. As a network of 67 interdisciplinary centers across the United States and its territories, we work to ensure that individuals with all types of disabilities are full members of their communities.

Our LEND programs help to ensure that the more than 3.8 million children with disabilities in the United States can find appropriate medical care from highly qualified professionals who have been trained on the most up-to-date interdisciplinary practices.

The general education and training of health care professionals and other elements of the health care system have not necessarily kept pace with the needs of these children. LEND programs are designed to address this shortage of highly qualified health care professionals for the needs of those children today and into the future.

The LEND program in Representative Obey's State is at the University of Wisconsin-Madison, and the Waisman Center is leading the way in looking at new treatments for Parkinson's, spinal muscular atrophy, Rett Syndrome, Fragile X, and Down Syndrome, training professionals on how to use science-based interventions in order to improve the quality of life of thousands of children and young adults.

Our university centers work to develop and evaluate promising practices that improve the lives of children and adults with disabilities and their families, conducting research in such areas as causes and prevention of disabilities and chronic conditions, and then translating that research into practice.

I will give you an example from my own university center. We have a child care facility called The Early Learning Center. It serves 240 children living in poverty, living in foster care settings, or with disabilities. The ELC is a site where over 500 university students observe best practices, participate in practical experiences, and conduct research.

In one of the most exciting examples of combined research, training, and service, we are in the middle of conducting a robot-as-

sisted mobility study with infants and toddlers. Preliminary results indicate that providing these children with disabilities with mobile devices at 18 years of age or younger actually increases their social, their language, and their cognitive abilities.

The good thing is that people have already recognized this and we have been able to attract partners to help create these mobility devices and then get them into children's and families' hands and feet already.

I now want to shift gears for just a little bit and talk about some of the challenges our Nation faces and how our network can help. I will address four things: Autism Spectrum Disorder, returning veterans with disabilities, racial and ethnic health and mental health disparities, and the increasing aging population.

Regarding health disparities, children and adults of color with developmental disabilities experience poorer health and have more difficulty finding and paying for health care as compared to other populations. Our network proposes to partner with minority-serving institutions of higher education to better engage research, education, and service efforts for African-Americans, Hispanic-Americans, Native Americans, Pacific Islanders, and Asian-Americans. In partnership with our existing university centers, minority-serving institutions of higher education would be well positioned to train future leaders, conduct necessary research, and disseminate pertinent information widely into communities.

We also want to extend our efforts from the university centers and the LENDs to reach out to returning veterans, to address the aging population, and especially to address the increasing number of individuals who are being diagnosed with Autism Spectrum Disorder.

Mr. Chairman, there are many challenges that we see and are ready to accept through our network. AUCD urges the Congress to provide sufficient funds that continue to take advantage of our highly effective and productive national network, and to continue the research, education, and service to address these critical emerging needs. Our written testimony outlines funding recommendations. Thank you, and I would be glad to take any questions that the Committee has.

Mr. OBEY. Thank you.

[The information follows:]



**Testimony of Michael Gamel-McCormick, Ph.D.,**  
Interim Dean, College of Human Services, Education and Public Policy  
at the University of Delaware

Representing the

**Association of University Centers on Disabilities**  
1010 Wayne Avenue Suite 920 Silver Spring, MD 20910  
301/588-8252 \* [www.aucd.org](http://www.aucd.org)

Before the

**House Appropriations**  
**Labor, Health and Human Services, Education Subcommittee**

**March 18, 2009**  
**10 a.m. – Noon**  
**Room 1358-C Rayburn House Office Building**

This testimony summarizes the activities of and provides funding recommendations for the 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Developmental Disabilities (ADD) within the Department of Health and Human Services and the 38 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB) within the Health Resources Services Administration.

Mr. Chairman, on behalf of the Association of University Centers on Disabilities (AUCD), I am pleased to submit this written testimony for the record both as a means to thank you for the Committee's support of our Centers over the past several years, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs. These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between universities and their communities, bringing together the best of what current science has to offer to the challenges of children and adults living with disabilities in the community. By working together, programs engage in significant research that informs national policy and best practices. The network emphasizes national and international implementation of innovations in disability-related education, health care, and supports and services. It offers leadership on major social problems affecting all people with disabilities or special health needs.

I am Michael Gamel-McCormick, Ph.D., Interim Dean, College of Human Services, Education and Public Policy at the University of Delaware. I am submitting this testimony in my role as President of the AUCD Board of Directors.

First, let me describe the UCEDDs, one of the member networks of AUCD. The mission of the UCEDDs is to work with people with disabilities, their families, state and local government agencies, and community providers by engaging in training, technical assistance, service, research, and information sharing to build the capacity of communities to sustain all their citizens.

Since the 1960s, when Congress established a small number of research centers to study mental retardation, UCEDDs have grown into a national network of 67 Centers, each of which has developed its own area(s) of expertise based on the needs of the local community, their state, and the evolving expectations of people with disabilities to be full members of their communities. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402), UCEDDs currently serve as a national education, service, research, and information dissemination resource for our nation. The DD Act mandates that UCEDDs promote opportunities for individuals with developmental disabilities to exercise self-determination, and to be independent, productive, integrated citizens in all facets of community life. The UCEDDs meet these objectives by conducting research, providing training and technical assistance, and providing exemplary evidence-based direct services and supports. This includes state-of-the-art diagnosis and evaluation as well as support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, and employment.

Congress's investment in this valuable and effective network has been key to expanding inclusion of people with disabilities in American communities. AUCD urges the Congress to provide sufficient funds to continue to take advantage of this highly efficient and productive national network to address emerging critical national needs such as the alarming numbers of individuals diagnosed with Autism Spectrum Disorders. Nearly every UCEDD program provides autism-related services; however the potential of the UCEDD network to provide additional autism-related supports has only begun to be tapped.

We also need to address our nation's racial and ethnic health and mental health disparities as well as inequities in access to services and supports. It is well documented that children and adults with developmental disabilities experience poorer health and more difficulty finding and paying for health care as compared to other populations. Our network proposes to partner with Minority Serving Institutions of higher education to better engage our research, education and service efforts for African Americans, Hispanic Americans, Native Americans, Pacific Islander and Asian Americans. Each of these populations has different levels of incidence and prevalence of diseases and disabilities that must be studied and unique cultural issues including language, customs, and traditions that must be considered in order to better serve these populations. In partnership with existing UCEDDs, Minority Serving Institutions of higher education would be well positioned to train future leaders, conduct the necessary research, and disseminate pertinent and culturally relevant information targeted to diverse populations.

**We are respectfully seeking an appropriation of \$44,000,000 under the ACF/ADD program for University Centers for Excellence in Developmental Disabilities (a \$6 million increase)** which would allow up to four capacity-building grants of \$250,000 to enable up to four UCEDDs to work in partnership with collaborating Minority Serving Institutions (as defined in the Higher Education Act) to focus on research, health, education, and services for African Americans, Hispanic Americans, Native Americans, Pacific Islanders, Asian Americans, and other ethnically and culturally diverse populations. The increase would also help UCEDDs address critical, emerging national needs, such as the growing number of individuals with Autism Spectrum Disorders and related neurodevelopmental disorders; allow the Administration on Developmental Disabilities to expand National Training Initiative grants on emerging national issues; and provide for a cost-of-living increase to the Centers.

Now I will address the Leadership Education in Neurodevelopmental and Related Disabilities--or LEND--programs. LEND programs are improving the health status of infants, children, and adolescents who have or at risk for neurodevelopmental and related disabilities, and their families. This is accomplished through the interdisciplinary training of professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research, and consultation. The LEND program focuses on the special health care needs of children with a wide range of neurodevelopmental, metabolic, and genetic disorders, including Autism Spectrum Disorder. Currently, there are 38 LENDs in 31 states and the District of Columbia. All LEND programs operate within a university system, many as part of a UCEDD or other larger entity, and are commonly affiliated with university hospitals, children's hospitals, or health care centers. This collaboration provides the programs with expert faculty, facilities, and other resources necessary to provide exceptional interdisciplinary training and services. Each LEND receives core funding from the Maternal and Child Health Bureau of the Health Resources and Services Administration of the U.S. Department of Health and Human Services. As a network, LENDs develop and promote best practices, produce exceptional clinicians and leaders in a variety of disciplines.

In 2006, Congress passed and the President signed the Combating Autism Act (CAA, PL 109-416) authorizing the Secretary to expand existing and develop new LENDs in states that did not have such a program. The intent of Congress was two-fold: to increase Autism Spectrum

Disorder-related training directed at developmental pediatricians, clinical psychologists, other diagnosticians, and interventionists in states with LEND programs, and to establish new LEND programs with this charge in states that did not have a LEND program. . HRSA began this expansion with the \$5.4 million appropriated in FY 2008 as part of its Autism and Other Developmental Disorders program by establishing four new LEND programs in Arkansas, Colorado, Connecticut, and Illinois and awarding 18 supplemental grants to existing LENDs to increase their Autism Spectrum Disorder-related training. The FY 2009 appropriations bill will provide \$2 million to continue this expansion by allowing competitions to establish up to two new LENDs and up to five supplemental grants for existing programs. These additional resources will increase the number of professionals who are able to identify, assess, diagnose, and serve children with Autism Spectrum Disorders and other developmental disabilities. Much more needs to be done, but the CAA has helped LEND programs begin to better address the challenge of the increased numbers of children with autism.

**Therefore, we are respectfully seeking an increase in funding that is specifically set aside for the LEND program to \$28,200,000 (a \$2 million increase) within the HRSA Autism and Other Developmental Disorders program.** This additional funding will enhance the capacity of up to five existing LEND programs to expand their training of professionals in the interdisciplinary care and treatment of children with Autism Spectrum Disorder and related neurodevelopmental disabilities as well as provide funds to develop up to two new LEND programs in states that do not have one. This \$2 million would be part of the \$47 million authorized for HRSA activities in FY 2010 under the Combating Autism Act.

As I have stated, the UCEDD and LEND networks engage in education and training at the university and community level, conduct translational and applied research, and offer services to individuals and families. Please allow me this opportunity to provide you with some examples.

**Training and Education** – Nearly every aspect of individuals with disabilities' quality of life can be traced back to the work of well-trained professionals—teachers, clinicians, community service providers, etc. Positioned within universities, LEND and UCEDD programs provide interdisciplinary education to professionals-in-training and provide continuing education for professionals practicing in multiple fields. Whether the focus is on leadership, direct service, family-centered care, advocacy, cultural competence, clinical or administrative personnel training, these pre-service and continuing education programs are geared to the needs of students, practicing professionals, and families, and have been essential in raising and defining the educational standards of service across health, education, employment, and social service systems. In 2008, the network provided training to 3,560 students and fellows.

*The Kansas Center for Autism Research and Training was initiated by the UCEDD in Kansas in 2008 to support research and training on the causes, nature and management of Autism Spectrum Disorders. The Center has already launched an ambitious new The Autism Training Program geared to autism specialists, respite providers, family support providers and others working with individuals with Autism Spectrum Disorders and their families. The training program also is working with the state Department of Social and Rehabilitation Services to train skilled providers for the state's first Autism Waiver Program. With more trained providers,*

*Kansas families struggling with the effects of Autism Spectrum Disorders will receive services where they need them, in their own homes and communities.*

**Research** – UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. By studying areas such as brain development, Autism Spectrum Disorders, and early literacy, UCEDD researchers are studying how persons with disabilities learn and how best to teach them. UCEDDs lead in developing and evaluating promising practices that improve the lives of children and adults with disabilities and their families. Many are engaged in federal research projects on the causes and prevention of disabilities and chronic conditions and translate research into practice through the development and dissemination of informative products. In 2008, UCEDDs and LENDs operated 1,163 projects with a research component, including investigations into the efficacy of educational, behavioral, health, and technological interventions, policy analysis, and clinical trials.

*In recent years, researchers working on neurodegenerative diseases such as Alzheimer's, Lou Gehrig's, Parkinson's have focused on astrocytes in their quest to help the brain protect itself from stressful conditions that are deadly to neurons. By shifting a normal protective mechanism into overdrive, a scientist at the UCEDD at the University of Wisconsin-Madison has completely shielded mice from a toxic chemical that otherwise would have caused Parkinson's disease. If scientists can determine how to fix a sick astrocyte, or even prevent a carrier from getting sick, they could offer profound protection against numerous neurodegenerative diseases.*

**Service** – UCEDDs and LENDs provide direct services and supports to people with developmental and other disabilities, their families, and communities. This includes state-of-the-art diagnosis and evaluation and support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment. In 2008, the network provided clinical services to 105,388 individuals and magnified this impact with an additional 146,438 consults on promising practices and supports to other providers.

*The Delaware UCEDD's Early Learning Center is a nationally accredited, comprehensive early care and education clinical research facility serving 240 children, ages 6 weeks to 12 years, and their families, and specifically targeting children with risk factors, including poverty, foster care, and disabilities. In its fourth year, the Early Learning Center expanded to provide quality early care and education program for infants and toddlers in Wilmington's Southbridge area; provided a site for observation, practicum, and research to more than 5,00 undergraduate and graduate students from six UD colleges; and conducted more than a dozen interdisciplinary research projects on such topics as language acquisition, early literacy, parental discipline, maternal depression, and healthy eating and physical activity of preschoolers. The Early Learning Center's robot-assisted mobility study has been featured in a Discovery Channel documentary and has attracted private partnership funding to help create mobility devices for children with disabilities under three years of age.*

*Another example of the services provided by the network is the State Employment Leadership Network, lead by the Institute for Community Inclusion, a Massachusetts UCEDD, with the state MR/DD agencies of 18 states. This multi-state initiative of the UCEDD provides technical*

*assistance and promotes practices and policies to increase employment options for persons with disabilities.*

**Responding to National Needs** – UCEDDs and LENDs are equipped to respond quickly to emerging national needs. They are currently expanding their work in the areas adult-acquired disabilities, particularly related to aging and military-combat, and they continue to work with the federal government on policies and initiatives to address the needs of people with disabilities in emergencies and disasters. Other national issues that have been addressed by UCEDDs and LENDs include positive behavioral interventions and supports, reading disorders in children, training programs for direct support personnel in developmental disabilities, and provision of training in methods to support employment for individuals with disabilities.

I again ask that you consider our request for funding of \$44 million for the network of UCEDDs and \$26,200,000 for the LENDs so that we may expand our network to more adequately serve our nation's growing population of Americans with developmental and other lifelong disabilities and to address our nation's health disparities.

Thank you for the opportunity to share this information about the UCEDDs and LENDs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

Sincerely,

A handwritten signature in black ink, reading "M. T. Gamel-McCormick". The signature is fluid and cursive, with the first name "Michael" and last name "McCormick" clearly legible.

Michael Gamel-McCormick  
President, AUCD



**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

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Your Name, Business Address, and Telephone Number:

Michael Gamel-McCormick, Ph.D.  
Office of the Dean  
College of Human Services, Education and Public Policy  
106 Alison Hall West  
University of Delaware  
Newark, DE 19716  
(302) 831-2394

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Association of University Centers on Disabilities (AUCD)  
1010 Wayne Avenue, Suite 920  
Silver Spring, MD 20910  
(301) 588-8252

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?



No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

**Federal Grants, Cooperative Agreements, and Contracts to AUCD**

A. Administration on Developmental Disabilities (ADD) for Technical Assistance to the UCEDDs: FY06: \$444,705; FY07: \$645,420; FY08: \$595,580; FY09: \$616,425

B. Maternal and Child Health Bureau (MCHB) for

\*Technical Assistance to the Leadership Education in Neurodevelopment and other Disabilities (LENDs) training programs: FY06: \$330,000; FY07: \$330,000; FY08: \$270,500; FY09: \$170,000  
 \*Technical Assistance under the Combating Autism Act: FY09: \$487,641  
 \*Pediatric Audiology Training: FY09: \$504,244

C. Centers for Disease Control and Prevention (CDC) for

\*National Professional Organization for Persons with Developmental Disabilities: FY06: \$270,000; FY07: \$140,000; FY08: \$250,000; FY09: \$805,000  
 \*Research Topics of Interest: FY06: \$921,600; FY07: \$2,074,000; FY08: \$250,000; FY09: \$1,700,000

D. Social Security Administration (SSA) for

\*Pediatric Evaluation Project: FY06: \$315,000; FY07: \$182,000  
 \*Pediatric Medical Unit Determination Project: FY07: \$1,770,449; FY08: \$1,914,498

**Federal Grants to the University of Delaware**

Administration on Developmental Disabilities for the University Center of Excellence on Developmental Disabilities (UCEDDs): FY06: \$500,000; FY07: \$490,000; FY08: \$520,000; FY09: \$528,000

Signature:



Date: March 16, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**CURRICULUM VITAE\*****Michael Gamel-McCormick**

**College of Human Services, Education and Public Policy**  
**106 Alison Hall West**  
**University of Delaware**  
**Newark, Delaware 19711**  
**(302) 831-6504 (voice)**  
**(302) 831-4690 (FAX)**  
[mgm@udel.edu](mailto:mgm@udel.edu) (e-mail)

**PRESENT STATUS:**

Interim Dean of the College of Human Services, Education and Public Policy at the University of Delaware and an Associate Director of the Center for Disabilities Studies. Activities include leadership of a college of 2,500 students, 150 faculty and 250 professional staff with four academic units, eight undergraduate majors, three undergraduate minors, and 23 graduate programs, including Ph.D. and Ed.D. programs. Administration of a \$55 million teaching, research, and service college focusing on education, human development, family studies, public policy and leadership. Additional oversight of 13 university research and service centers ranging from demographic survey research to early child development research and math and science education instruction.

**EDUCATION:**

Ph.D. in Human Development and Education,	1995	Virginia Commonwealth University
M.S., in Family and School Counseling,	1981	University of Wisconsin, Madison
B.S. in Child Development,	1979	University of Delaware
B.A. in Psychology,	1979	University of Delaware

**PROFESSIONAL EXPERIENCE:**

<b>2008-Present</b>	<b>Interim Dean, College of Human Resources, Education, and Public Policy</b>
<b>2008-Present</b>	<b>Associate Director, Center for Disabilities Studies, University of Delaware</b>
<b>2007-2008</b>	<b>Interim Chair, Department of Individual and Family Studies</b>
2005-present	Professor, Department of Individual and Family Studies, University of Delaware
2001-2008	Director, Center for Disabilities Studies, University of Delaware
1999-2005	Associate Professor, Department of Individual and Family Studies, University of Delaware
1996-2000	Research Coordinator, Center for Disabilities Studies, University of Delaware

\* **Bold** indicates activities since last promotion in 2005.

WEDNESDAY, MARCH 18, 2009.

## THE AD HOC GROUP FOR MEDICAL RESEARCH

### WITNESS

**MARY J.C. HENDRIX, PH.D.**

Mr. OBEY. Next, The Ad Hoc Group for Medical Research, Dr. Mary J.C. Hendrix.

Ms. HENDRIX. Good morning, Mr. Chairman and members of the Subcommittee. My name is Mary Hendrix, and I serve as the President and Scientific Director of the Children's Memorial Research Center at Northwestern University's Feinberg School of Medicine. I am testifying on behalf of The Ad Hoc Group for Medical Research, a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry.

As an active cancer researcher who runs an institute that employs more than 500 staff, I thank and commend Congress for including the extraordinary investment in medical research through the National Institutes of Health in the American Recovery and Reinvestment Act, as well as the \$938,000,000 in NIH funding in the Omnibus Appropriations Act for fiscal year 2009.

In particular, I am deeply grateful to the Chairman and this Subcommittee for your longstanding leadership in support of the NIH. These are difficult times for our Nation, for everyone around the globe, and investing in science is a key step to a better future and is a strategic approach.

The funding increases in the Recovery Act and the fiscal year 2009 Omnibus will provide an immediate infusion of funds into the Nation's highly competitive medical research enterprise so that we can pursue new diagnostics, prevention strategies and treatments, and also so we can provide state-of-the-art scientific facilities and support our scientists and their support personnel.

As a result of this Subcommittee's prior investment in NIH, we have made critical advances in many different areas in research, including Parkinson's Disease, including infectious diseases and cancer. And I would say that all of these advances are leading us to an area of more effective, personalized medical treatment.

However, the discovery process often takes a long, lengthy, and unpredictable path; and the infrastructure that we are creating needs to be maintained so large fluctuations in funding will be disruptive to training, to careers, to long-term planning and projects, and ultimately to progress. The research engine needs a sustained investment in science to maximize our investment globally. We must ensure that, after the stimulus money is spent, that we do not have to dismantle all of our progress and newly built capacity.

In 2011 and beyond, we need to be able to continue to advance the new directions chartered with the Recovery Act support. So, Mr. Chairman, as you noted in your recent press release, the fiscal year 2009 Omnibus and the Recovery Act provided \$38,500,000,000 for NIH to provide over 16,000 new research grants for lifesaving research into many diseases. So keeping up with the rising cost of medical research in the 2010 appropriations will help NIH begin to prepare for the post-stimulus era.

In 2011 and beyond, we need to make sure that the total funding available to NIH does not decline and that we can resume a steady, sustainable growth consistent with the President's vision for investment in basic research. Consistent with the President's proposal, we respectfully urge this Subcommittee to increase funding for NIH in fiscal year 2010 by at least 7 percent.

As we appreciate the ravages of disease are many and the opportunities for progress across all fields of medical science are profound, investing broadly in biomedical research is key to ensuring the future of America's medical enterprise and the health of our citizens.

We thank you again for your leadership and for the Subcommittee's leadership in improving the health and quality of life for all Americans and for the opportunity to speak to you today. Thank you.

Mr. OBEY. Thank you.

[The information follows:]

Mary J.C. Hendrix, PhD  
President & Scientific Director  
Medical Research Institute Council Professor  
Children's Memorial Research Center  
Northwestern University Feinberg School of Medicine  
Chicago, Illinois

March 18, 2009  
10 a.m.

Testifying on behalf of  
The Ad Hoc Group for Medical Research  
In support of the National Institutes of Health

Summary of Statement

The funding increases provided for the National Institutes of Health (NIH) in the American Recovery and Reinvestment Act and the FY 2009 omnibus will provide an immediate infusion of funds into the nation's proven and highly competitive medical research enterprise to sustain the pursuit of improved diagnostics, better prevention strategies and new treatments for many devastating and costly diseases. These advances also contribute to the nation's economic strength by creating skilled, high-paying jobs; new products and industries; and improved technologies.

However, the discovery process—while it produces tremendous value—often takes a lengthy and unpredictable path. The infrastructure that we are creating needs to be maintained. Large fluctuations in funding will be disruptive to training, to careers, long range projects and ultimately to progress. The research engine needs a predictable, sustained investment in science to maximize our return.

We must ensure that after the stimulus money is spent we do not have to dismantle our newly built capacity and terminate valuable, on-going research. In 2011 and beyond we need to be able to continue to advance the new directions charted with the ARRA support.

Keeping up with the rising cost of medical research in the 2010 appropriations will help NIH begin to prepare for the “post-stimulus” era. In 2011 and beyond we need to make sure that the total funding available to NIH does not decline and that we can resume a steady, sustainable growth that will enable us to complete the President's vision of doubling our investment in basic research. Consistent with this vision, we respectfully urge this Subcommittee to increase funding for NIH in Fiscal Year 2010 by at least 7 percent.

Science is unpredictable and it is difficult to know exactly which discoveries gained through basic research will foster the next medical advancement. Investing broadly in biomedical research is the key to ensuring the future of America's medical research enterprise and the health of her citizens.

My name is Mary J.C. Hendrix, and I am President and Scientific Director for the Children's Memorial Research Center at Northwestern University's Feinberg School of Medicine. Among my other positions, I am a former President of the Federation of Association of American Societies for Experimental Biology, and am a current member of the Board of Research!America and the Advisory Panel on Research for the Association of American Medical Colleges. I am testifying on behalf of the Ad Hoc Group for Medical Research, which is a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry.

As an active cancer researcher and representative of the Ad Hoc Group for Medical Research, I thank and commend Congress for including the extraordinary investment in medical research through the National Institutes of Health (NIH) that was included as part of in the American Recovery and Reinvestment Act (ARRA) [P.L. 111-5] as well as the \$938 million increase in NIH funding in the Omnibus Appropriations Act for FY 2009 [P.L. 111-8]. In particular, we are deeply grateful to the Chairman and this Subcommittee for your long-standing leadership in support of NIH. These are difficult times for our nation and for people all around the globe, but the affirmation of science is the key to a better future is a strategic step forward. All of us in the medical research community are committed to do our utmost to fulfill the faith that you and the American people have placed in us.

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions continues to serve as the driving force in this nation's search for ever-greater understanding of the mechanisms of human health and disease, from which arise new diagnostics and treatments, and cures, and better ways to improve the health and quality of life for all Americans. These advances also contribute to the nation's economic strength by creating skilled, high-paying jobs; new products and industries; and improved technologies.

The recent history of the NIH budget has hindered scientific discovery and limited the capacity of a key engine for today's innovation-based economy. The additional funding in the ARRA and the FY 2009 omnibus are critical first steps to returning the NIH to a course for even greater discovery. These investments give patients, their families and researchers renewed hope for the future, and will help ensure the success of America's medical research enterprise and leadership.

The funding increases in the ARRA and the FY 2009 omnibus will provide an immediate infusion of funds into the nation's proven and highly competitive medical research enterprise to sustain the pursuit of improved diagnostics, better prevention strategies and new treatments for many devastating and costly diseases as well as support innovative research ideas, state-of-the-art scientific facilities and instrumentation, and the scientists, technicians, laboratory personnel, and administrators necessary to maintain the enterprise. More importantly, these funds will reinvigorate this nation's ability to produce the human and intellectual capital that will continue to drive scientific discovery, transform health, and improve the quality of life for all Americans.

Moreover, we see this as the first step in renewing a national commitment to sustained, predictable growth in NIH funding, which we believe is an essential element in restoring and

sustaining both national and local economic growth and vitality as well as maintaining this nation's prominence as the world leader in medical research.

President Obama has committed to increase federal support for research, technology and innovation so that America can lead the world in creating new advanced jobs and products. A key element of his strategy is to double federal funding for basic research to "foster home-grown innovation, help ensure the competitiveness of U.S. technology-based businesses, and ensure that 21st century jobs can and will grow in America." If America is to succeed in the information-based, innovation driven world-wide economy of the 21<sup>st</sup> century, we must recommit to long-term sustained and predictable growth in medical research funding.

As a result of this Subcommittee's prior investment in NIH, we have made critical advances in several key areas including:

- Stem Cells -- Reprogramming skin cells from a patient with Parkinson's Disease into normal neurons that could be used to fight this degenerative disease.
- Infectious Diseases -- Developing more effective antibodies, and ultimately vaccines, to fight lethal flu viruses before they become pandemic.
- Cancer -- Launching the Cancer Genome Atlas as a partnership between the National Cancer Institute and the National Human Genome Research Institute to discover the genetic basis for various cancers.

In addition, as a consequence of the investment over the past two decades in the human genome project and other areas of genetics, we are now entering an era of personalized medicine, which has the potential to transform healthcare through earlier diagnosis, more effective prevention and treatment of disease, and avoidance of drug side effects. For example, the same medication can help one patient and be ineffective for, or toxic to, another. By applying our greater understanding of how an individual's genetic make-up affects a response to specific drugs, we will increasingly know which patients will likely benefit from treatment and which will not benefit, or worse, be harmed. Cancer chemotherapy and the use of the anticoagulant Coumadin are good examples of how this might be applied.

However, the discovery process—while it produces tremendous value—often takes a lengthy and unpredictable path. The talent base and infrastructure that we are creating needs to be maintained. Large fluctuations in funding will be disruptive to training, to careers, long range projects and ultimately to progress. The research engine needs a predictable, sustained investment in science to maximize our return.

We must ensure that after the stimulus money is spent we do not have to dismantle our newly built capacity and terminate valuable, on-going research. In 2011 and beyond we need to be able to continue to advance the new directions initiated with ARRA support.

Mr. Chairman, as you noted in your recent press release, the FY 2009 omnibus and the ARRA provided \$38.5 billion for NIH to provide over 16,000 new research grants for live-saving research into diseases such as cancer, diabetes and Alzheimer's. Keeping up with the rising cost of medical research in the 2010 appropriations will help NIH begin to prepare for the "post-



stimulus" era. In 2011 and beyond we need to make sure that the total funding available to NIH does not decline and that we can resume a steady, sustainable growth that will enable us to complete the President's vision of doubling our investment in basic research. Consistent with the President's proposal, we respectfully urge this Subcommittee to increase funding for NIH in Fiscal Year 2010 by at least 7 percent.

The ravages of disease are many, and the opportunities for progress across all fields of medical science to address these needs are profound. The community appreciates that this subcommittee has always recognized that science is unpredictable and that it is difficult to know exactly which discoveries gained through basic research will foster the next medical advancement. There are many examples of areas where important therapies for one disease have resulted from investments in unrelated areas of research. Investing broadly in biomedical research is the key to ensuring the future of America's medical research enterprise and the health of her citizens.

Thank you again for your leadership in improving the health and quality of life for all Americans and for the opportunity to speak to you today.

**Dr. Mary J.C. Hendrix** received her B.S. degree in Biology/Pre-Med from Shepherd College (now called Shepherd University) in 1974, her Ph.D. in Anatomy from George Washington University in 1977, and an honorary D.Sc. in 1996 from Shepherd College. Dr. Hendrix was an NIH Postdoctoral Research Fellow at Harvard Medical School in the Department of Anatomy and Cell Biology from 1977 to 1980; Assistant, Associate and Professor (and Associate Head) at the University of Arizona from 1980-1993 and served as an Arizona Disease Control Research Commissioner from 1985 to 1994. She was the Immuno-US Endowed Professor and Director of the Pediatric Research Institute, St. Louis University School of Medicine and Cardinal Glennon Children's Hospital from 1994-1996, prior to joining the faculty of The University of Iowa as the Leading Woman Scientist Endowment Recipient and Head of the Department of Anatomy and Cell Biology in June 1996. She also served as the Kate Daum Research Professor, and Associate Director of Basic Research and Deputy Director for The Holden Comprehensive Cancer Center at The University of Iowa, for the Roy J. and Lucille A. Carver College of Medicine from 1996-2004. Currently, she serves as President and Scientific Director, and the Medical Research Institute Council Professor, for the Children's Memorial Research Center at Northwestern University Feinberg School of Medicine. She is the US Editor of Pathology Oncology Research, and Member of the Editorial Boards of Lymphatic Research & Biology, Developmental Dynamics, Cancer Biology and Therapy, Journal of Cellular Biochemistry, Cancer Research, the American Journal of Pathology, and Cancer Microenvironment. She is a Past-President of FASEB (Federation of American Societies for Experimental Biology). She also serves on the National Institutes of Health's Council of Councils, the Board of Directors for the Annenberg Center for Health Sciences, the National Cancer Institute Board of Scientific Advisors, the Board of Directors for Research!America, and the Board of Directors for the Chicago Council on Science & Technology. Dr. Hendrix is a Past-President of the Association of Anatomy, Cell Biology, and Neurobiology Chairpersons (AACBNC), and former Co-Director of the Virtual Naval Hospital. She has over 200 publications in biomedical research, and is the recipient of a MERIT Award from the National Cancer Institute. Dr. Hendrix has been awarded the 2004 Australian Society for Medical Research Lecturer and Medal Recipient for research and advocacy, the 2006 Henry Gray Award by the American Association of Anatomists that recognizes achievement and unique and meritorious contributions to the field of anatomical science, the 2006 Distinguished Woman Faculty Award from Northwestern University's Feinberg School of Medicine, the 2007 Murray Barr Award from the University of Western Ontario, and the 2008 Princess Takamatsu Cancer Research Lecturer Award in Japan. Her scientific objectives include identifying genes which contribute to cancer metastasis and other related diseases which exhibit similar biological activities. Her major goal is to define important structure/function relationships, which provide the biological basis for new therapeutic strategies. Recent studies have generated molecular classification(s) of specific tumors, and have provided new prognostic markers and novel targets for therapeutic intervention. Current research activities focus on elucidating how regulatory molecules and phenotype control genes govern cell-to-cell and cell-to-matrix interactions, epithelial/mesenchymal transitions, and motility. Specific projects include signal transduction events initiated by cell adhesion molecules and growth factors; factors regulating interconversion of the tumor cell phenotype; regulation of matrix metalloproteinases by tumor and stromal cell interactions; tumor angiogenesis and vasculogenesis; role of the microenvironment in inducing and maintaining an aberrant cellular phenotype; and the identification of stem cell subpopulations within tumors.

**Subcommittee on Labor, HHS, Education  
and Related Agencies  
Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

Mary J.C. Hendrix, Ph.D.  
President & Scientific Director  
Children's Memorial Research Center  
Northwestern University's Feinberg School of Medicine  
2300 Children's Plaza, Box 222  
Chicago, Illinois 60614-3363  
Phone: 773.755.6528; Fax: 773.755.6534; E: [mjchendrix@childrensmemorial.org](mailto:mjchendrix@childrensmemorial.org)

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Ad Hoc Group for Medical Research

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

2 R37 CA59702 (Hendrix)	\$4,525,000	NIH/NCI
2 RO1 CA75681 (Hendrix)	\$1,500,000	NIH/NCI
1 RO1 CA121205 (Hendrix)	\$1,824,127	NIH/NCI

*Mary J.C. Hendrix*

Signature: \_\_\_\_\_

March 13, 2009

Date: \_\_\_\_\_

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Mr. Tiahrt.

Mr. TIAHRT. Thank you, Mr. Chairman.

You mentioned personalized treatment. Is that as a result of the genome project, that you can tailor treatment for an individual?

Ms. HENDRIX. Yes, sir. I am glad you asked about that. So, based on the sequencing of the human genome, which took over two decades and finished in 2003, we are now able to look at the genes responsible for many different diseases; and as these are being discovered almost on a daily basis, we now can apply them to predict diseases at the earliest possible time and then to think about prevention strategies. So that is where we are going.

Mr. TIAHRT. It is not just applicable to cancer, it is to other diseases as well?

Ms. HENDRIX. To diseases across the board, sir. Yes. Thank you.

Mr. TIAHRT. Thank you.

Mr. JACKSON. Mr. Chairman, if I might pick up on what Representative Tiahrt said.

Mr. OBEY. Yes.

Mr. JACKSON. And, I gather, design specific medications that can be personalized to the individual based upon the genome sequence in that individual, leading to a designer drug?

Ms. HENDRIX. That is exactly correct, and then predicting which patients will be more receptive to receiving these particular drugs based on their genetic background.

Mr. JACKSON. Thank you, Mr. Chairman.

Ms. HENDRIX. Thank you.

Thank you, sir.

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WEDNESDAY, MARCH 18, 2009.

## **CROHN'S AND COLITIS FOUNDATION OF AMERICA**

### **WITNESS**

#### **GARY SINDERBRAND**

Mr. OBEY. I understand Mr. Jackson would like to introduce our next witness.

Mr. JACKSON. Thank you, Mr. Chairman. I appreciate the opportunity to introduce Gary Sinderbrand to the Subcommittee. Gary is the Chairman of the Board of Trustees for the Crohn's and Colitis Foundation of America. CCFA is the Nation's oldest and largest nonprofit organization dedicated to finding a cure for these devastating disorders. Gary will share with us his daughter's courageous story of living with Crohn's Disease. Unfortunately, I know all too well the challenges these patients face, having watched my chief of staff endure a similar struggle.

Mr. Chairman, I want to personally thank you and the Subcommittee and the staff for all of the work that you have given to this important cause over the years. I look forward to continued progress in this Congress.

Gary, thank you for being with us today. We look forward to your testimony.

Mr. SINDERBRAND. Congressman Jackson, first, let me extend my heartfelt thanks on behalf of the 1.4 million Americans suffering

from these diseases for all of your ongoing support. We truly appreciate it.

Let me say at the outset how appreciative we are for the leadership this Subcommittee has provided in advancing funding for the National Institutes of Health. Hope for a better future for our patients lies in biomedical research, and we are grateful for the recent investments that you have made in this critical area.

Crohn's Disease and ulcerative colitis are devastating inflammatory disorders of the digestive tract that cause severe abdominal pain, fever, and intestinal bleeding. Complications include arthritis, osteoporosis, anemia, liver disease, and colorectal cancer. We do not know their cause and there is no medical cure. They represent the major cause of morbidity from digestive diseases and forever alter the lives of the people they afflict, particularly children. I know because I am the father of a child living with Crohn's Disease.

Seven years ago, during my daughter, Alexandra's sophomore year in college, she was taken to the ER for what was initially thought to be acute appendicitis. After a series of tests, my wife and I received a call from the attending GI who stated coldly, your daughter has Crohn's Disease. There is no cure and she will be on medication the rest of her life.

The news froze us in our tracks. How could our vibrant, beautiful little girl be stricken with a disease that was incurable and has ruined the lives of countless thousands of people?

Over the next several months, Alexandra fluctuated between good days and bad. Bad days would bring on debilitating flares which would rack her body with pain and fever as her system sought equilibrium. Our hearts were filled with sorrow as we realized how we were so incapable of protecting our child.

Her doctor was trying increasingly aggressive therapies to bring the flares under control. Each treatment came with its own set of side effects and risks. Every time Alexandra would call from school, my heart would jump before I picked up the call, in fear of hearing that my child was once again in pain from the flares.

Ironically, the worst call came from one of her friends to report that Alexandra was back in the ER being evaluated by a GI surgeon to determine if an emergency procedure was needed to clear an intestinal blockage that was caused by the disease. Several hours later, a brilliant surgeon at the University of Chicago removed over a foot of diseased tissue from her intestine. The surgery saved her life but did not cure her. We continue to live every day knowing the disease could flare at any time with devastating consequences.

Fortunately, the scientific community is making tremendous strides in the fight against IBD. We have terrific partners at the NIH and CDC, and I will now turn my attention to CCFA's fiscal year 2010 recommendations for these agencies.

Throughout its 40-year history, CCFA has forged successful research partnerships with the NIH. CCFA provides crucial seed funding to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue IBD research projects through the NIH. For fiscal year 2010, CCFA joins with other patient and medical organizations in recommending a 7 percent increase in funding for the NIH.

Mr. Chairman, as I mentioned earlier, CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not have an exact number due to these diseases' complexity and the difficulty in identifying them. We are extremely grateful for your leadership in providing funding over the past five years for an epidemiology program on IBD at the Centers for Disease Control and Prevention. The program is yielding invaluable information about the prevalence of IBD and increasing our knowledge of the demographic characteristics of the patient population.

Finally, Mr. Chairman, the unique challenges faced by children and adolescents battling IBD are of particular concern to CCFA. In recent years, we have seen an increased prevalence of IBD among children, particularly those diagnosed at a very early age. To combat this alarming trend, CCFA, in partnership with the pediatric gastroenterology community, has instituted an aggressive pediatric research campaign empowering investigators with HIPAA-compliant information on young patients from across the Nation that will jump start our efforts to expand basic and clinical research on our pediatric population.

We encourage the Subcommittee to support our efforts to establish a pediatric IBD patient registry within the CDC in fiscal year 2010.

Mr. Chairman, once again, thank you for the opportunity to testify. I would be happy to answer any questions.

Mr. OBEY. Thank you.

[The information follows:]



a future without Crohn's disease & colitis

**STATEMENT OF**

**MR. GARY SINDERBRAND**

**CHAIRMAN, NATIONAL BOARD OF TRUSTEES**

**CROHN'S AND COLITIS FOUNDATION OF AMERICA**

**PRESENTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

**REGARDING FY10 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND  
HUMAN SERVICES**

**MARCH 18, 2009**

**SUMMARY OF FY10 RECOMMENDATIONS:**

- 1) **7% INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH.**
- 2) **\$700,000 FOR THE NATIONAL INFLAMMATORY BOWEL DISEASE  
EPIDEMIOLOGICAL PROGRAM AT THE CENTERS FOR DISEASE CONTROL AND  
PREVENTION.**
- 3) **COMMITTEE RECOMMENDATIONS SUPPORTING THE ESTABLISHMENT OF A  
PEDIATRIC INFLAMMATORY BOWEL DISEASE PATIENT REGISTRY.**

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to speak with you today on behalf of the 1.4 million Americans living with Crohn's disease and ulcerative colitis. As Congressman Jackson mentioned, my name is Gary Sinderbrand and I have the privilege of serving as the Chairman of the National Board of Trustees for the Crohn's and Colitis Foundation of America. CCFA is the nation's oldest and largest voluntary organization dedicated to finding a cure for Crohn's disease and ulcerative colitis -- collectively known as inflammatory bowel diseases.

**\*National Headquarters**

386 Park Avenue South, New York, NY 10016-8804

Tel.: 800.932.2423 212.685.3440 Fax: 212.779.4098 E-mail: [info@ccfa.org](mailto:info@ccfa.org) Internet: [www.ccfa.org](http://www.ccfa.org)

Let me say at the outset how appreciative we are for the leadership this Subcommittee has provided in advancing funding for the National Institutes of Health. Hope for a better future for our patients lies in biomedical research and we are grateful for the recent investments that you have made in this critical area.

Mr. Chairman, Crohn's disease and ulcerative colitis are devastating inflammatory disorders of the digestive tract that cause severe abdominal pain, fever and intestinal bleeding. Complications include arthritis, osteoporosis, anemia, liver disease and colorectal cancer. We do not know their cause, and there is no medical cure. They represent the major cause of morbidity from digestive diseases and forever alter the lives of the people they afflict – particularly children. I know, because I am the father of a child living with Crohn's disease.

Seven years ago, during my daughter, Alexandra's sophomore year in college, she was taken to the ER for what was initially thought to be acute appendicitis. After a series of tests, my wife and I received a call from the attending GI who stated coldly: Your daughter has Crohn's disease, there is no cure and she will be on medication the rest of her life. The news froze us in our tracks. How could our vibrant, beautiful little girl be stricken with a disease that was incurable and has ruined the lives of countless thousands of people?

Over the next several months, Alexandra fluctuated between good days and bad. Bad days would bring on debilitating flares which would rack her body with pain and fever as her system sought equilibrium. Our hearts were filled with sorrow as we realized how we were so incapable of protecting our child.

Her doctor was trying increasingly aggressive therapies to bring the flares under control. Asacol, Steroids, Mercaptopurine, Methotrexate and finally Remicade. Each treatment came with its own set of side effects and risks. Every time A would call from school, my heart would jump before I picked up the call in fear of hearing that my child was in pain as the flares had returned. Ironically, the worst call came from one of her friends to report that A was back in the ER and being evaluated by a GI surgeon to determine if an emergency procedure was needed to clear an intestinal blockage that was caused by the disease. Several hours later, a brilliant surgeon at the University of Chicago, removed over a foot of diseased tissue from her intestine. The surgery saved her life, but did not cure her. We continue to live every day knowing that the disease could flare at any time with devastating consequences.

From the point of hearing the news, I refused to accept the fact that this disease could not be cured. As I studied all the relevant data I could find, I reached out to the organization that seemed to be repeatedly mentioned, The CCFA. This organization is leading the fight in research, education and support on behalf of the 1.4myn Americans that suffer from these illnesses.

I made a pest of myself at the National office seeking knowledge about how the fight was being staged. The more I learned the more I believed that we could do better. I was invited to join the national board and 6 years later, I have the privilege of leading an extraordinary staff of professionals and a network of volunteers across our entire country.



We are making dramatic progress that is the result of the scientific excellence of our funded researchers and our volunteer scientific leadership as well as the rapid advancement of available technology. It is now not “if” we will cure IBD, but “when”

The time to a cure is now a function of available funding.

Mr. Chairman, I will focus the remainder of my testimony on our appropriations recommendations for fiscal year 2010.

## **RECOMMENDATIONS FOR FISCAL YEAR 2010**

### **1) NATIONAL INSTITUTES OF HEALTH**

Throughout its 40 year history, CCFA has forged remarkably successful research partnerships with the NIH, particularly the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which sponsors the majority of IBD research, and the National Institute of Allergy and Infectious Diseases (NIAID). CCFA provides crucial “seed-funding” to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue advanced IBD research projects through the NIH. This approach led to the identification of the first gene associated with Crohn’s -- a landmark breakthrough in understanding this disease.

To further accelerate genetic research and advance understanding of IBD, NIDDK issued a research solicitation to establish an IBD Genetics Consortium approximately 8 years ago. This effort was informed by recommendations from external experts. Funding for the Consortium’s six centers began in 2002, and intensive data and sample collection, genetic analysis, and recruitment of new patients and their families have been under way. In 2006, the Consortium published the major discovery of a new IBD gene. Some sequence variations in this gene, called *IL23R*, were found to increase susceptibility to IBD, while another variant actually confers protection. This gene was known previously to be involved in inflammation, and its newly-discovered association with IBD may lead to the development of better therapies for IBD. In recognition of the success of the Consortium’s large-scale collaborative effort, NIDDK decided to continue support for the program beyond its initial 5-year period which was slated to end in FY07.

Renewed funding in FY08 has enabled the Consortium to continue its genetic studies and recruit additional patients and relatives (as well as subjects without IBD for comparison). This expansion will facilitate the identification of additional predisposing genes and enable genetic analyses of certain patient subgroups, such as those from minority populations or those who experience an early-onset form of IBD. These findings may then be used to pursue genetically-based diagnostic tests that allow for earlier diagnosis and treatment intervention. In addition, the data can be used to identify new molecular targets for therapeutic development that are specifically targeted to a unique subset of patients.

Mr. Chairman, we are grateful for the leadership of Dr. Stephen James, Director of NIDDK's Division of Digestive Diseases and Nutrition, for pursuing this and other opportunities in IBD research aggressively. Fortunately, the field of IBD is widely viewed within the scientific community as one of tremendous potential. CCFA's scientific leaders, with significant involvement from NIDDK, have developed an ambitious research agenda entitled "Challenges in Inflammatory Bowel Diseases" that seeks to address many opportunities that currently exist. We look forward to working with NIDDK and the Subcommittee to pursue these research goals in the coming years.

For FY10, CCFA joins with other patient and medical organizations in recommending a 7% increase in funding for the NIH. We specifically encourage the subcommittee to support the invaluable work of the NIDDK and NIAID.

## **2) CENTERS FOR DISEASE CONTROL AND PREVENTION**

### **INFLAMMATORY BOWEL DISEASE EPIDEMIOLOGY PROGRAM**

Mr. Chairman, as I mentioned earlier CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not have an exact number due to these diseases' complexity and the difficulty in identifying them.

We are extremely grateful for your leadership in providing funding over the past five years for an epidemiology program on IBD at the Centers for Disease Control and Prevention. This program is yielding valuable information about the prevalence of IBD and increasing our knowledge of the demographic characteristics of the IBD patient population. If we are able to generate an accurate analysis of the geographic makeup of the IBD patient population, it will provide us with invaluable clues about the potential causes of IBD.

Appreciating Congressman Kennedy's strong interest in autoimmune diseases like IBD, I should note that the latest phase of this project focuses on Rhode Island. The "Ocean State Crohn's & Colitis Area Registry" is identifying each new case of inflammatory bowel disease diagnosed in the state. The result will be a unique, population-based cohort of newly diagnosed patients to be followed prospectively over time---the first of its kind in the U.S., and one of very few such cohorts in the world. The goals of the study include: 1) describing the incidence rates of Crohn's disease and ulcerative colitis; 2) describing disease outcomes; and 3) identifying factors that predict disease outcomes. To date over 85 newly diagnosed patients of all ages have been enrolled into the study.

Mr. Chairman, to continue this important epidemiological work in FY10, CCFA recommends a funding level of \$700,000, an increase of \$16,000 over FY09.

**PEDIATRIC INFLAMMATORY BOWEL DISEASE PATIENT REGISTRY**

Mr. Chairman, the unique challenges faced by children and adolescents battling IBD are of particular concern to CCFA. In recent years we have seen an increased prevalence of IBD among children, particularly those diagnosed at a very early age. To combat this alarming trend CCFA, in partnership with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, has instituted an aggressive pediatric research campaign focused on the following areas:

- Growth/Bone Development - How does inflammation cause growth failure and bone disease in children with IBD?
- Genetics – How can we identify early onset Crohn's disease and ulcerative colitis?
- Quality Improvement - Given the wide variation in care provided to children with IBD, how can we standardize treatment and improve patients' growth and well-being?
- Immune Response - What alterations in the childhood immune system put young people at risk for IBD, how does the immune system change with treatment for IBD?
- Psychosocial Functioning – How does diagnosis and treatment for IBD impact depression and anxiety among young people? What approaches work best to improve mood, coping, family function, and quality of life.

The establishment of a national registry of pediatric IBD patients is central to our ability to answer these important research questions. Empowering investigators with HIPPA compliant information on young patients from across the nation will jump-start our effort to expand epidemiologic, basic and clinical research on our pediatric population. We encourage the Subcommittee to support our efforts to establish a Pediatric IBD Patient Registry with the CDC in FY10.

Once again Mr. Chairman, thank you very much for the opportunity to be with you today. I look forward to any questions you may have.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

**Mr. Gary Sinderbrand  
Crohn's and Colitis Foundation of America  
386 Park Avenue South, 17<sup>th</sup> Floor  
New York, NY 10016  
(212) 685-3440**

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

**A non-governmental organization:  
The Crohn's and Colitis Foundation of America**

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes X No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

**The Crohn's & Colitis Foundation of America has a contract with the Centers for Disease Control and Prevention (CDC) which commenced in September 2005. The contract supports research and administration for CDC's Inflammatory Bowel Disease program. To date, the contract has provided \$2,223,118.**

Signature:

*Gary Sinderbrand*

Date:

3/16/09

WEDNESDAY, MARCH 18, 2009.

**AMERICAN COLLEGE OF CARDIOLOGY**

**WITNESS**

**JACK LEWIN, M.D.**

Mr. OBEY. Next, we will hear from Dr. Jack Lewin, American College of Cardiology.

Dr. LEWIN. Good morning, Chairman Obey and Ranking Member Tiahrt and members of the Committee. I am a physician and the Chief Executive of the American College of Cardiology. It is a real privilege to be here with you today. Thank you.

I would like to just take some excerpts from my testimony, which has a lot of details I hope that you will appreciate.

The American College of Cardiology represents veritably all the practicing cardiologists in this country. We also represent many thousands of international cardiologists. We represent advance practice nurses and pharmacists and others who practice cardiovascular medicine in teams with us.

We are concerned about the fact that the burden of cardiovascular disease in this country is rapidly growing. We estimate about \$475,000,000,000 of health services, medications, lost productivity due to cardiovascular disease will occur in 2009. It is still, by far and away, the number one cause of morbidity and mortality, the number one killer in this country. In Medicare, \$420,000,000,000 we spent in Medicare last year, 43 percent of it will be cardiovascular cost. That is over \$180,000,000,000.

Twenty-four hundred people die each day from heart disease, one every 30 seconds or so. About 1.5 million people will have a heart attack, one will die about every minute in this country. We can do a lot to improve that.

Now, despite all that, since 2000, there has been a 29 percent reduction of morbidity and mortality in this country in heart disease because of new imaging modalities, new treatment modalities in terms of angioplasties and stents, improvements in surgical outcomes and prevention. And that is great, but disparities exist in cardiovascular disease. Gender and ethnic disparities are just inexcusable. More women die than men of heart attacks in this country today, and most people do not seem to understand that.

We can do far better. We are spending far more than we need to for what we need in this future to build prevention and other health care services. So this ought to be a new era in which some of the colleges' most proud traditions could be better implemented with your help.

We have, for 25 years, translated science into guidelines, performance measures, and, lately, appropriate use criteria for technology to make sure the best evidence gets to the patients at the point of care. The Rand Corporation estimates that about 50 percent of the time people in this country are getting that evidence. We have got to improve upon that, not only with electronic health records and clinical decision support systems to make sure that does get better, but by tracking how we are doing.

The college runs something called the National Cardiovascular Data Registries. CMS actually requires some of the use of some of

our registries in Medicare programs. We run these in 2,400 major hospitals where cardiovascular services are provided and we measure outcome across these, over hundreds of measures in these hospitals.

In the last year, for example, we demonstrated that while the science says if you are having a heart attack in the emergency room, you need to get that heart attack treated and the blockage opened within 90 minutes to prevent permanent damage to your heart, as we measured across the country, and people thought we were doing this in about an hour, hospitals were shocked to learn that the average was well over two hours. In just one year we have gotten almost all of American hospitals down to under 90 minutes just by giving them the data.

So these registries are critically important and we need your help to expand the use of these registries through Federal agencies and others to systematically improve quality, address misuse and overuse of technologies, and go out and try to find those people who need services that are not getting them today. That is our professional accountability.

So we are asking that NIH get a 7 percent increase, to \$3,200,000,000, to help NIH and NIHLBI with some of the research needs to deal with some of the gaps in knowledge that still exist to help us improve the evidence-based care at the point of care.

We would like to see AHRQ, Agency for Health Research and Quality, get an increase of \$32,000,000 to \$405,000,000 to help us with the registry activities and to help us with comparative effectiveness research that would, again, advance these causes.

We would like to see CDC get some more money, another \$20,000,000 to \$74,000,000, for heart disease and stroke prevention activities; and the Health Resources and Services Administration also needs more resources for emergency defibrillation and for rural and community health activities.

The research needs are critically important. The comparative effectiveness research is critically important to us. So, in conclusion, Mr. Chair and members of the Committee, we believe this increased investment in NIH and NIHLBI, AHRQ, CDC, and HRSA will pay off with huge dividends for our society, huge return on investment there. The social and economic costs are great, but the opportunities are great. We have made great progress in cardiovascular disease, but the epidemic is increasing as America grays and as the diabetes and obesity problems multiply.

So thank you very much for listening to the testimony and receiving the details of it. We look forward to working with you. It has been an honor to be with you today.

Mr. OBEY. Thank you. I would just point out that, in the stimulus package, we did provide \$300,000,000 to AHRQ and \$400,000,000 to NIH for the kind of research you are talking about.

Dr. LEWIN. And we are so grateful for that. Thank you, sir.

Mr. OBEY. Thank you.

[The information follows:]

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ORAL TESTIMONY

Presented by

Jack Lewin, M.D.  
Chief Executive Officer  
American College of Cardiology

Presented to the

UNITED STATES HOUSE OF REPRESENTATIVES  
APPROPRIATIONS COMMITTEE  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND  
RELATED AGENCIES

March 18, 2009

Mr. Chairman and members of the subcommittee, I am Dr. Jack Lewin, Chief Executive Officer of the American College of Cardiology (ACC), a 37,000 member, non-profit professional medical society and teaching institution whose mission is to advocate for quality cardiovascular care — through education, research promotion, development and application of standards and guidelines — and to influence health care policy.

Heart disease is the leading cause of death for both women and men in the United States and is projected to cost the country \$475 billion in health care services, medications, and lost productivity in 2009. Nearly 2,400 Americans die of cardiovascular disease each day — an average of 1 death every 37 seconds. In 2009, an estimated 785,000 Americans will have a new coronary attack, and about 470,000 will have a recurrent attack. It is estimated that an additional 195,000 silent first myocardial infarctions occur each year. About every 25 seconds, an American will have a coronary event, and about every minute someone will die from one.

Fortunately, the death rates for cardiovascular disease have declined and Americans due to advances in science through new drug and device therapies, surgical innovations, enhanced emphasis on prevention, and innovative public educational programs—all made possible through NHLBI-funded research. In fact, since 2000 we have seen a 29 percent reduction in morbidity and mortality rates; nonetheless additional improvement is needed, including reducing variation, uneven quality, reducing disparities of race and gender. Our citizens—many of them potential cardiac patients—do not want us to become complacent as we celebrate the many advances in the prevention, diagnosis, and treatment of cardiovascular disease that have resulted from our nation's pioneering research and educational programs.

ACC encourages Congress to provide a strong federal investment in research and prevention programs that address cardiovascular disease. Federal research is providing for breakthrough advances that fundamentally change our understanding of the prevention and treatment of cardiovascular disease, leading to better outcomes, decreased costs, and increased quality of life for patients.

#### **ACC Funding Recommendations for FY2010**

ACC urges the Subcommittee to consider the following FY 2010 funding recommendations when determining appropriations for programs within the Department of Health and Human Services:

National Institutes of Health (NIH): The College supports a 7 percent increase in NIH funding for FY 2010, for a total of \$3.227 billion. Research conducted through the NIH has resulted in better diagnosis and treatment of cardiovascular disease, thereby improving the quality of life for those living with the disease and lowering the number of deaths attributable to it. Adequate funding through the NIH is necessary for basic, clinical, and translational research that facilitates the delivery of new discoveries to the bedside.



National Heart, Lung, and Blood Institute (NHLBI): ACC supports an FY 2010 budget of \$3.227 billion to help the NHLBI continue its critical research into the causes, diagnosis, and treatment of heart, blood vessel, lung and blood diseases. This investment will allow NHLBI to continue fulfilling the goals laid out in its strategic plan, “Shaping the Future of Research: A Strategic Plan for the National Heart, Lung, and Blood Institute.”

Agency for Healthcare Research and Quality (AHRQ): The College recommends an FY 2010 base funding level of \$405 million for AHRQ, an increase of \$32 million. We support the recent increases in funding for AHRQ’s comparative effectiveness research program. We recommend that increased funds for AHRQ in 2010 be dedicated to bolstering these other important research topics to balance the recent investments in comparative effectiveness research. Comparative effectiveness research alone will not solve our health system challenges; the full spectrum of health services research on health care costs, quality, and access should be supported.

CDC Heart Disease and Stroke Prevention Program: ACC recommends \$74 million, a \$20 million increase, for the Centers for Disease Control and Prevention (CDC) State Heart Disease and Stroke Prevention program. The CDC Division for Heart Disease and Stroke Prevention’s public education efforts are making strides in the prevention of and early intervention in treating cardiovascular disease – thereby potentially reducing future care costs significantly.

HRSA Rural and Community AED Program: The College recommends \$8.927 million for the Health Resources and Services Administration (HRSA) Community Access to Emergency Defibrillation program. This funding level would restore the program to its FY 2005 funding level when it provided grants to 47 states. This is an important initiative that saves lives by placing external defibrillators in public facilities.

### **Research Needs in Cardiovascular Care**

ACC and the American Heart Association (AHA) have a long history in the development of clinical practice guidelines. The College strives to produce the preeminent medical specialty practice guidelines, with more than 18 guidelines on a range of cardiovascular topics. They are developed through a rigorous, evidence-based methodology employing multiple layers of review and expert interpretation of the evidence on an ongoing, regular basis. Many clinical research questions, however, remain unanswered or understudied. The guideline recommendations based on expert opinion rather than clinical data vary by cardiovascular topic from only 20 percent for coronary bypass surgery to more than 70 percent for valvular heart disease.

Through its clinical policy development process, the College has identified knowledge gaps for cardiovascular disease. If addressed, these currently unresolved issues have potential to positively impact patient outcomes, costs, and the efficiency of care delivery. An investment in answering the following scientific questions through the NIH, in particular the NHLBI, and

through the Agency for Healthcare Research and Quality (AHRQ), will help to better narrow the target population who can benefit from treatment and therefore increase the efficacy and efficiency of patient-centered care delivery:

1. What is the effect of common cardiovascular therapies on elderly populations whose metabolism and kidney function is lower and may not respond to medications in the same way as the younger patients typically included in clinical trials?
2. What is the effect of common cardiovascular therapies on patients with multiple other diseases/conditions?
3. What are the best approaches to increasing patient compliance with existing therapies?
4. What screening and risk models (existing or new) could further define who will benefit from various therapies?
5. What are the optimal management strategies for anticoagulation and antiplatelet agents in heart attack patients, patients with stents, and atrial fibrillation patients to maximize benefit and reduce bleeding risks?
6. What are the best approaches to managing complex but understudied cardiovascular topics such as congenital heart disease, valvular heart disease, and hypertrophic cardiomyopathy? These topics have become areas of higher research interest as techniques have developed to extend the lives of these patients.
7. What are the risks and benefits of common off-label uses of widely used therapies and procedures, such as drug eluting stents?
8. What are the best catheter-based techniques to increase treatment success and reduce complications for both coronary and cardiac rhythm procedures?

The above list of topics is not exhaustive but gives an overview of some of the themes of the evidence gaps that exist across the ACC/AHA guidelines.

In addition to specific clinical research topics, ACC recommends funding to help address structural issues that could help identify, prioritize, and interpret research findings over the long term.

1. The NIH should fund more trials of direct comparison between pharmacological and other therapies. Without these important trials, the current emphasis on promoting comparative effectiveness will be founded upon efficacy trials and not effectiveness.

2. The NHLBI should work with the clinical cardiology community to proactively design clinical trials to address unanswered clinical questions and identify methods that allow for greater comparability among studies. NHLBI should work with ACC and the AHA to develop an evidence model that would drive future research initiatives based on current evidence gaps in the guidelines; and
3. NIH should fund the development of a robust informatics infrastructure across Institutes to process research evidence. Studies should be designed such that their results could be “fed” into a computer model that would provide additional insights for developers of clinical recommendations.
4. NIH should fund studies of patient preference and values.

#### **The Role of Comparative Effectiveness Research**

Through the ACC’s past 25 years of developing clinical guidelines, performance measures and clinical appropriate use criteria, we have found that comparative effectiveness research has proven to be a vital tool that helps translate clinical research into more informed medical decision-making. ACC supports an increased investment in federal comparative effectiveness research based on the principle that physicians and patients should have the best available evidence upon which to make choices in health care items and services. An important component in data collection comes through clinical registries. The College’s National Cardiovascular Data Registries (NCDR) can play a substantial role in this area.

The College strongly believes that keeping cost analyses independent of comparative clinical effectiveness research ensures that the clinical research achieves a high degree of credibility among all stakeholders. The entity responsible for supervising/conducting this research must not also make coverage and benefit decisions; such decisions should be independently made, based on the best available scientific evidence, and should take into consideration the need for flexibility based on the individual needs and complexities of the patient. In addition, ACC believes that guideline development is best done by medical specialty societies—like ACC, where the clinical expertise resides—to synthesize the information from multiple sources in ways that are actionable and where there is greater credibility among patients and providers. Lastly, the College urges the concurrent development and implementation of strategies for the widespread dissemination and use of the results of comparative research by health care providers, through systematic programs of physician education and support from specialty societies such as ACC.

In conclusion, by continuing this nation's major investment in biomedical research in general, NIH, NHLBI, AHRQ, and CDC-sponsored research in particular, Congress will help literally thousands of investigators make discoveries and advance knowledge. As researchers open new

paths to and through medical frontiers, it is exciting to contemplate the implications for the future health of our citizens. Already, as a result of a multitude of discoveries and innovations, thousands of highly-skilled cardiovascular specialists are performing procedures such as coronary angioplasty and prescribing medical treatments that were unimaginable just a few years ago. But this is not just about treatment. Health care professionals are also promoting powerful prevention strategies that have been validated by HHS sponsored researchers.

The need to reduce the enormous social and economic costs of cardiovascular disease is a compelling reason to increase our cardiovascular disease research budget significantly. The need has never been greater. The United States must prepare itself, both scientifically and fiscally, for the inevitable increase in the incidence of cardiovascular disease that will accompany the graying of the so-called baby-boomer generation.

I hope the Subcommittee shares my optimism about the unique opportunities that our scientists and clinical investigators now have to achieve their long-standing goal of conquering this nation's number one killer. In summary, the American College of Cardiology would like to encourage you to generously fund government-sponsored cardiovascular research -- it is a wise investment in our nation's future.

Mr. Chairman, I appreciate having this opportunity to speak to the Subcommittee.

I have submitted a written statement for the record.

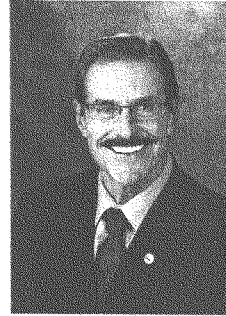
Thank you.

*American College of Cardiology*

John C. Lewin, M.D.  
Chief Executive Officer

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2400 N Street, N.W.  
Washington, DC 22192  
Phone: (202) 375-6180  
Email: jlewin@acc.org  
Website: www.acc.org

Future Meeting: 58<sup>th</sup> Annual Scientific Session and  
Innovation in Intervention: i2 Summit 2009  
March 28-31, 2009 – Orlando, FL

*Organization Profile*

The American College of Cardiology (ACC) is leading the way to optimal cardiovascular care and disease prevention. The College is a 36,000-member nonprofit medical society and bestows the credential Fellow of the American College of Cardiology upon physicians who meet its stringent qualifications. Our members include cardiologists and other members of the cardiac care team from around the world.

The College is a leader in the formulation of health policy, standards and guidelines, and we use these guidelines to help improve cardiovascular care and practice through the use of products, programs and services.

ACC is a staunch supporter of cardiovascular research and we communicate the latest advances to our membership, to the scientific community and to the general public. We synthesize the latest science so that it can be used to deliver optimal patient care and to respond to the needs of policymakers around payment and appropriateness decisions.

ACC develops responsive, innovative and relevant educational opportunities and operates national registries under the auspices of the National Cardiovascular Data Registry for the measurement and improvement of quality care. The College also fosters disease prevention and increases understanding of the importance of prevention. We provide information and tools to cardiologists, general practitioners and internists to improve cardiovascular health in the general population and equip practitioners with the information and informational tools needed to effectively address prevention of cardiovascular disease.

The College promotes adequate workforce training and we advocate for policies and program changes to respond to workforce needs. The College also promotes and upholds the highest professional standards in patient care and physician conduct.

*Association Executive Quick Profile*

Dr. Jack Lewin has been Chief Executive Officer ACC since November 2006. Under Lewin's leadership, ACC has aspired to contribute greatly to national leadership in advocacy related to expanding access to care for uninsured persons, and in reforming Medicare, Medicaid, and the financing and delivery of quality health care. These efforts are part of ACC's mission to promote 'heart health' and reductions in cardiovascular morbidity and mortality worldwide. ACC has over 350 employees and an annual budget of over \$100 million.

Prior to Coming to ACC, Lewin was CEO of the 35,000 member California Medical Association and its various subsidiary companies. Lewin was also formerly Hawaii's Director of Health from 1986-1994, overseeing 6500 employees and a \$1 Billion budget. In this role, he helped Hawaii achieve near-universal access to health care and revitalize statewide public health systems. In Hawaii, he was also CEO of the statewide 13-facility Community Hospital System.

Before that, as a Commissioned Officer in the USPHS, he was the founder and first Director of the Navajo Nation Department of Health, serving the needs of America's largest Indian tribe, straddling the three states of Arizona, New Mexico and Utah.

Trained in internal medicine, Lewin has also enjoyed many years of practicing primary care medicine during his career in Arizona, Hawaii, and California. He serves on numerous national boards and advisory bodies, including being founder and President of the *Physicians' Foundations*, which are among the top ten health-related philanthropies in the nation, focused on promoting quality, patient safety, and health information technology adoption, and President of the national Patient Safety Institute. He was an advisor on health policy to President Clinton.

Dr. Lewin received his B.A. in Biological Sciences from the University of California, Irvine, and his M.D. from the University of Southern California. His hobbies include composing for piano, skiing, biking, kayaking, and long-distance running, having completed over 25 marathons. He and his wife Sandra have three children.

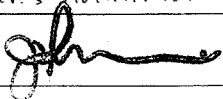
**Subcommittee on Labor, HHS, Education  
and Related Agencies**

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Your Name, Business Address, and Telephone Number: Jack Lewin, MD 2400 N Street, NW Washington, DC 20037 (202) 375-6600
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.  American College of Cardiology
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?  <input checked="" type="radio"/> Yes <input type="radio"/> No
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.  FDA - \$800,000 since 10/1/06, representing ACC CMS - \$24,999 annually, representing ACC Veteran's Administration - \$100,000, representing ACC

Signature: \_\_\_\_\_



Date: \_\_\_\_\_

3/16/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

WEDNESDAY, MARCH 18, 2009.

**PARKINSON'S ACTION NETWORK****WITNESS****MARY McGUIRE RICHARDS**

Mr. OBEY. Next, Mary McGuire Richards, Parkinson's Action Network.

Ms. RICHARDS. Thank you. Thank you, Chairman Obey, thank you, Ranking Member Tiahrt for inviting me to testify on behalf of the Parkinson's Action Network regarding the National Institutes of Health. I am the Deputy Chief Executive Officer at the Parkinson's Action Network. We are also known by our acronym PAN.

PAN represents the entire Parkinson's community, including more than 1 million Americans living with Parkinson's Disease, their families, and all of the major national Parkinson's organizations across the Country. You may have indeed met with some of your Parkinson's constituent advocates yesterday, when more than 300 people living with Parkinson's Disease were here on Capitol Hill to communicate with their elected representatives about the issues that are facing them back at home.

Parkinson's Disease is a chronic, debilitating, neurological disorder that results from premature death of dopamine-producing neurons in the brain. Parkinson's patients experience devastating physical and mental symptoms, including tremors, debilitating slow movements, postural instability, profound sleep disturbances, and a variety of cognitive impairments.

Parkinson's is the second most common neurodegenerative disease in the United States and it is currently without a known cure.

Parkinson's state-of-the-art treatment is currently based on a 40-year-old therapy. This therapy only provides some relief for some of the motor symptoms of the disease. There is nothing that slows or stops progression of disease. All of our current treatments are simply symptomatic relief and not disease modifying. As such, people living with Parkinson's Disease are desperately awaiting innovative disease modifying therapies that will relieve their pain and ultimately halt the unrelenting march of the disease.

Before I begin discussing 2010 funding issues, I would like to thank members of this Committee for their support for the National Institutes of Health, including the \$10,000,000,000 in the stimulus bill for the NIH. PAN not only applauds your commitment to biomedical research funding, but we will continue working with the NIH to ensure strategic investment of this one-time infusion of money to the NIH.

PAN continues to support the research advocacy communities' NIH request; however, we are also invested not only in how much money is spent at the NIH, but how those dollars are best spent.

To truly deal with the public health needs facing this Nation, disease modifying therapies, those that slow or stop progression of disease, are needed for untreated and under-treated diseases such as Parkinson's Disease. To accomplish this, NIH must launch a large, coordinated effort to overcome the scientific valley of death. Simply put, the valley of death is the gap between basic discoveries and potential therapies to treat disease. It is also known as



translational research. This science is new, it is challenging, it is costly, but it is essential if our aim is ultimately to develop those therapies that will meet an increasingly burdensome public health need.

NIH funds world-class basic science, but translational research is new science that requires new thinking. A consequence of tremendous discovery, such as the human genome project, has been additional science sophistication, but also somewhat less hopefully, it is a further separation from the researcher and that researcher's science to the people who might benefit from such science. A new model is required that will fill that gap.

NIH must rethink how we support the unique needs of translational science. The same systems that have supported basic science so well are not aiding in the application of that knowledge. Different expertise, leadership, and training are necessary to tackle complicated translation issues that are preventing or slowing research from moving into potential therapies.

NIH must develop a unique infrastructure, as well as systems to support translational science. Infrastructure must include things such as intellectual property and FDA expertise, which are essential to this part of the research endeavor.

Many existing efforts at the Institute must be bolstered or remodeled, and new systems called for under NIH reform must simply be funded. Unfortunately, a lack of dedicated resources at NIH has resulted in slowed implementation of NIH reform, which the Parkinson's community strongly supported. NIH reform aimed to enhance NIH's transparency, accountability, portfolio management, and strategic planning efforts, all of which will hasten basic discoveries and their translation into better therapies and treatments for all Americans facing diseases and disorders.

Without the commitment of resources to implement these reform activities, the struggle between any new efforts, such as the ones we would think are necessary in translational science, and the need to continue funding new ideas and research is increasingly difficult.

Let me be clear that PAN continues to support basic research discoveries coming out of NIH. Robust research at the beginning of the pipeline is essential for continuing to grow our knowledge of biomedical and disease processes, as well as to provide a feeding ground for new and novel ideas in science.

Of course, should novel ideas show promise, additional funding must be directed at translating these discoveries into the treatments to alleviate the suffering of people living with diseases.

As a patient advocacy organization, PAN is ultimately concerned with improving the health of people living with Parkinson's Disease. However, this is not a disease-specific problem, nor does it require a disease-specific approach to a solution.

I do appreciate the Committee's time. We do advocate for the Committee to continue asking NIH to maintain the dedicated funding resources and systems necessary to support patient-oriented research and finding a cure for all Americans. I am happy to take any questions. We really do appreciate your time and your consideration.

Mr. OBEY. Thank you.

Ms. RICHARDS. Thank you.

[The information follows:]

Testimony of Mary McGuire Richards  
Deputy Chief Executive Officer  
Parkinson's Action Network  
Washington, DC

Outside Witness Hearing for the U.S. House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

March 18, 2009

Thank you, Chairman Obey, and Ranking Member Tiahrt for inviting me to testify on behalf of the Parkinson's Action Network regarding the National Institutes of Health. I am the Deputy Chief Executive Officer of the Parkinson's Action Network, also known by our acronym, PAN.

PAN represents the entire Parkinson's community, including the more than 1 million Americans currently fighting Parkinson's disease (PD), the estimated 60,000 newly diagnosed every year, and their families, and all the national Parkinson's organizations, including The Michael J. Fox Foundation for Parkinson's Research, Parkinson's Disease Foundation, National Parkinson Foundation, Parkinson Alliance, and American Parkinson Disease Association.

Parkinson's disease is a chronic, progressive neurological disorder that results from degeneration and premature death of dopamine-producing brain cells. Parkinson's patients experience devastating physical and mental symptoms such as tremors, debilitating slow movements, postural instability (balance problems), sleep disturbances, and a variety of cognitive impairments.

Parkinson's is the second-most common neurodegenerative disease in the United States. The cause of PD is unknown, although research points to a combination of genetic and environmental factors. PD is currently without any known cure.

Today, treatment options only provide relief for only some symptoms of the disease. There is nothing that slows, stops, or reverses progression of the disease or that will ward off ultimate and complete disability. Current state-of-the-art treatment for people with Parkinson's disease is rooted in levodopa and its derivatives. Levodopa was approved almost 40 years ago and, sadly, is still the primary treatment for Parkinson's. Deep Brain Stimulation (DBS) surgery is available for certain patients and treats some symptoms of Parkinson's disease. Yet, levodopa, its derivatives, and DBS only treat some motor symptoms of the disease and are only effective in treating those symptoms for a limited period of time.

Unfortunately, as the disease progresses, the motor and non-motor symptoms worsen and become increasingly difficult to treat. With disease progression, Parkinson's patients experience motor unpredictability and fluctuation. Patients do not know when the medication will "kick in," (resulting in an "on" period) or even if it will (resulting in an "off" or immobile period.)

As Parkinson's progresses, even with treatment, substantial disability -- including the inability to maintain balance, walk, speak, and move -- is inevitable and makes assisted living and nursing home care necessary. Ultimately, PD is a disorder of immobility, where persons suffering from the disease can feel trapped in their own bodies. People living with Parkinson's disease are desperately awaiting an innovative disease modifying therapies that will relieve their pain and halt the disease.

Although the purpose of today's hearing is Fiscal Year (FY) 2010 appropriations for the National Institutes of Health (NIH), I would like to take this opportunity to thank the Committee on behalf of the Parkinson's community for providing \$10 billion for the NIH in the American Recovery and Reinvestment Act, H.R. 1. Thanks to your efforts, this significant investment will facilitate much-needed research and thousands of high paying jobs. Of particular interest to PAN, is ensuring the strategic use of this significant, one-time infusion of biomedical research funding necessary to hasten basic discoveries and development of better therapies and a cure for Parkinson's disease.

Regarding FY 2010 appropriations, PAN continues to work in conjunction with the Ad Hoc Group for Medical Research to promote steady, sustainable increases in funding for NIH. Accordingly, in order to not lose ground in ongoing research and consistent with the President's request, we support the medical research advocacy community's recommendation for at least a seven percent increase above the FY 2009 funding level for the NIH.

However, PAN also continues to focus on how the biomedical research enterprise can engage in science to drive faster treatments and cures for people living with Parkinson's disease. To discern the best and fastest route to curative science, we examine not only how much money is needed but also how to those dollars are best spent. To this end, we urge the Committee to provide NIH funding to support NIH Reform implementation as well as the resources necessary to overcome the scientific "Valley of Death."

#### NIH Reform

An unfortunate outcome of the past several years of flat-funding of the NIH is slowed implementation of many of the reforms called for by the NIH Reform Act of 2006, which was strongly supported by the Parkinson's community. NIH Reform aimed to enhance NIH's transparency, accountability, and strategic planning efforts -- all of which will hasten basic discoveries and their translation into better treatments and cures for Americans facing diseases and disorders.

I would like to first applaud the agency for its implementation of the NIH Reform mandated agency-wide reporting system, which was launched in January of 2009. This reporting tool, called the Research, Condition, and Disease Categorization (RCDC) system, is a comprehensive electronic reporting system that, for the first time, transparently catalogues all of the research activities of the NIH in a standardized format.

Increased transparency of NIH research activities highlights areas of ongoing research to improve research portfolio management, provides greater accountability of research dollars, and spurs creative thinking about new scientific approaches. This information is beneficial for

independent investigators, public advocacy groups, NIH internally, and Congress. The RCDC system is a huge endeavor that has already been fruitful for disease advocacy organizations, including PAN.

Although the Parkinson's community is pleased with the progress that has already been made, we are also aware that many of the NIH Reform implementation efforts should be further along than they are today. In fact, RCDC system's development was slowed, in part, due to a lack of sufficient funding. Without the commitment of resources to implement these Reform activities, the struggle between new efforts and the need to continue funding new ideas in research is increasingly difficult. In order for NIH to implement the reforms recently passed by Congress, appropriations for NIH must, at a minimum, keep pace with biomedical inflation.

The Scientific Management Review Board was to issue its first report to Congress within a year and a half of enactment of the bill. However, it is lagging behind schedule -- its members were only named in September of 2008 and no report has yet been issued. The creation of the Board was to be significant because the reform legislation made it responsible for making recommendations regarding changes in NIH organizational structure. The Board is also tasked with reviewing the current research portfolio and making strategic planning recommendations and ensures that NIH maximizes scientific opportunities that impact public health. This provision was important to disease advocacy organizations as it aimed to drive patient-oriented outcomes, but we are concerned about early signs that it is behind schedule.

Although proper and timely implementation of NIH Reform efforts is necessary, these reform provisions only constitute a modest and incremental approach to creating patient-oriented outcomes at the agency. Flat-funding at the agency also harms on-going efforts to enhance translational and clinical research needed to hasten better treatments and cures for Parkinson's disease and many others.

#### Valley of Death

It is helpful to understand the context in which PAN views all NIH programs. As you may know, NIH is the single largest source of Parkinson's and other biomedical research funding in the world. As such, it is charged with developing new knowledge to improve the health of Americans living with diseases and disabilities.

NIH funds world-class basic science, but a coordinated, large-scale effort within the agency is needed to support this emerging type of science. Handing off publicly-financed research to private industry for product development is one of the most difficult steps in crossing the Valley of Death, and a coordinated, well-supported translational research enterprise at NIH will help researchers in moving their work along.

NIH must rethink how to support the unique needs of translational science and provide the expertise, leadership, and training necessary to tackle complicated issues that prevent or slow research from moving into potential therapies. Intellectual Property and FDA expertise is essential to this part of the research endeavor, and existing efforts at the Institute must be bolstered or remodeled. NIH must develop a unique infrastructure as well as systems that are

needed to support translational science and hasten discovery of new treatment and cures for all Americans.

It is widely agreed, however, that there are major obstacles in the research endeavor that are slowing, if not blocking, our way to better treatments and cures for untreated and under-treated diseases. The issue is the scientific Valley of Death where promising therapies and treatments fail to connect from research to products.

Currently, no one in the federal government is responsible for ensuring that the scientific baton is passed from basic discovery onto private therapy development. The drug development pipeline in this country generally depends upon pharmaceutical or biotechnology companies picking up a discovery and seeing it through to the end of the FDA approval process. This middle part of the process, where promising drugs can be lost and no one is ensuring that good ideas in the lab are "translated" into real possibilities for patients, is referred to as the "Valley of Death."

In addition, over the last 15 years, science has become more sophisticated as we better understand the complexities of human biology and disease; however, a consequence has been moving researchers who conduct basic science farther away from patients who might benefit from the application of such science. A new model is required that will fill the gap, or the Valley of Death, between basic discoveries and potential therapies for disease.

It has been the position of the Parkinson's community for quite some time that NIH should focus on patient-oriented outcomes by doing more to combat the Valley of Death. Unfortunately, however, due to a lack of funding and in order to maintain basic research grants, NIH not only has not focused more on translational research, but has actually cut these programs. As Dr. Zerhouni said in his Senate Labor, Health and Human Services, and Education Appropriations Subcommittee testimony on March 19, 2007, "the impact [of NIH budget cuts] is primarily in our ability to translate from the laboratory to the clinic to the bedside into the community what we need to do to prevent diseases."

It is disconcerting for people living with Parkinson's and other untreated or under-treated conditions to know that many potential drugs are languishing in the "Valley of Death" simply because there is not enough funding to move basic research to product development. This science is some of the most difficult and costly research needed to develop therapies and meet the public health need, including developing pre-human testing, efficacy trials, production design and a range of other steps needed to determine whether a drug will be safe and effective. It is also essential for reducing the burden of disease and disability for millions of Americans.

The research that will bridge the Valley of Death is translational science, which aims to move basic discoveries into therapies for people living with diseases. Without translational research, the development of our best solutions to major public health needs – better treatments and cures – are slowed if not stopped altogether.

Let me be clear that PAN continues to support basic research discoveries coming out of NIH, which are very important. Robust research at the beginning of the pipeline is essential for continuing to grow our knowledge of biological and disease processes as well as to provide a

feeding ground for new, novel ideas in science. Of course, should novel ideas show promise, additional funding should be directed at translating these discoveries into treatments to alleviate the suffering of people living with disease.

Today, the Parkinson's Action Network again seeks your support for NIH funding sufficient to make gains in NIH Reform implementation and overcoming the Valley of Death. PAN continues to support basic science, but, as a patient advocacy organization, we are ultimately concerned with improving the health of people living with Parkinson's disease. We ask the committee to ensure that the NIH maintains the dedicated funding, resources, and systems necessary to support patient-oriented research essential to finding a cure.

On behalf of the Parkinson's community, I thank you for your continued interest in Parkinson's disease issues and your support for better treatments and a cure for Parkinson's. I would be happy to answer any questions you may have.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Mary McGuire Richards  
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202-638-4101 ext. 103

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Parkinson's Action Network

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

\$45,000 from the Telemedicine & Advanced Technology Research Center (TATRC) of the U.S. Army Medical Research and Materiel Command (USAMRC) Award #W\*1XWH-09-0022 to the Parkinson's Action Network.

Signature:



Date:

March 18, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.





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Testimony of Mary McGuire Richards  
 Deputy Chief Executive Officer  
 Parkinson's Action Network  
 Washington, DC

Outside Witness Hearing at 10:00 am  
 March 18, 2009

U.S. House of Representatives Committee on Appropriations  
 Subcommittee on Labor, Health and Human Services, Education, and Related  
 Agencies

#### Federal Grants to the Parkinson's Action Network:

FY 2009 -- \$45,000 from the Telemedicine & Advanced Technology Research  
 Center (TATRC) of the U.S. Army Medical Research and Materiel Command  
 (USAMRC) Award #W\*1XWH-09-0022 to the Parkinson's Action Network.

FY 2008 -- \$45,000 from the Telemedicine & Advanced Technology Research  
 Center (TATRC) of the U.S. Army Medical Research and Materiel Command  
 (USAMRC) Award #W\*1XWH-09-0022 to the Parkinson's Action Network.

WEDNESDAY, MARCH 18, 2009.

**AMERICAN LUNG ASSOCIATION**

**WITNESS**

**ALBERT A. RIZZO, M.D.**

Mr. OBEY. Next, Dr. Albert Rizzo, American Lung Association.

Dr. RIZZO. Thank you, Chairman Obey and Committee members. I am a board certified practicing physician in pulmonary sleep medicine and critical care, and currently the Chief of Pulmonary and Critical Care Medicine Section at the Christiana Care Health Systems in Newark, Delaware.

I am also a long-time volunteer of the American Lung Association and currently serve as Speaker of the Nationwide Assembly, which is the body of that volunteer organization that oversees the mission work. I am pleased to present the American Lung Association's recommendations today.

The public health and research programs funded by this Committee will prevent lung disease and improve and extend the lives of millions of Americans who suffer from lung disease.

First and foremost, we want to thank you, Mr. Chairman and Committee members, for the investments in health you made in H.R. 1, the American Recovery and Reinvestment Act. We particularly appreciate the investments in research and funding for prevention and wellness programs. These investments will have net a near-term and long-term dividend for the health of American people, as well as people worldwide.

Many lung diseases are chronic diseases and, as such, are huge drivers of cost and human suffering. We urge the Committee to focus resources on reducing the burden of such chronic diseases. While our focus is on lung disease, we know that America must maintain a renewed commitment to medical research in general, and strongly support increasing the investment in research across the entire NIH.

A growing, sustained, predictable, and reliable investment in the National Institutes of Health provides hope for millions afflicted with lung disease. A new and sustained investment in prevention and wellness will lead to a healthier, more productive population and reduce health care costs. Investments in proven interventions, like smoking cessation and the Healthy Communities Program at the Centers for Disease Control and Prevention, reduce the burden of disease.

Progress in these areas was made in fiscal year 2009 and in the stimulus bill. But as you well know, Mr. Chairman, to see the outcomes that we all seek, these investments must be sustained over time.

The toll of lung disease is enormous. It is responsible for one in every six deaths, and more than 33 million Americans suffer from a chronic lung disease. Chronic obstructive pulmonary disease, or COPD, which is more commonly known as emphysema or chronic bronchitis, is the fourth leading cause of death and the only leading cause of death in this Country that continues to increase.

The cost in human toll of COPD is staggering. I see patients every day who suffer from this disease. Mary G. was a patient of

mine who developed COPD and sent the last six months of her life on a ventilator or breathing machine. Mary's daughter, Beth, who I now treat for asthma, lived with and loved a very significantly impaired mother who could not participate in the day-to-day activities that a mother should participate in because she was so short of breath.

Despite the enormity of this problem, COPD receives far too little attention at CDC or in health departments across the Nation. The American Lung Association strongly supports the establishment of a national COPD program within CDC's National Center for Chronic Disease Prevention and Health Promotion, with a funding level of at least \$1,000,000 for fiscal year 2010 to create a comprehensive national action plan for combating this disease. This plan will address the public health role in prevention, treatment, and management of this disease.

So, in concluding, besides COPD, the American Lung Association's recommendations are that NIH needs to have significant and sustained increasing and funding research for lung cancer to improve the terribly low lung cancer survivorship; adequate funding for the CDC's Office on Smoking and Health that can help prevent so much of the disease I see in my office every day; asthma research and asthma programs for the nearly 23 million afflicted individuals with that chronic lung disease; tuberculosis, especially multi-drug resistant TB, needs research because of the significant threat it poses to public health; and influenza, since the Nation must continue to invest and be prepared for a significant pandemic, as well as providing yearly annual vaccination.

Many patients with these diseases are literally fighting for air every day, sometimes from breath to breath, so, Chairman and members of the Committee, I thank you for your time, and please consider the Nation's urgent lung health needs in 2010 appropriation bill.

[The information follows:]



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**Statement of Albert A. Rizzo, MD,  
Speaker,  
American Lung Association Nationwide Assembly  
Newark, DE**

**Presented to  
The House Labor, Health & Human Services,  
Education and Related Agencies  
Appropriations Subcommittee**

**Fiscal Year 2010  
March 18, 2009 10:00 AM**

**Department of Health and Human Services  
Summary of Programs**

**Centers for Disease Control and Prevention**

- Increased overall CDC funding -- \$8.6 billion
- Funding CDC COPD Program at least \$1 million
- Funding Healthy Communities -- \$30 million
- Office on Smoking and Health -- \$160 million
- Asthma programs -- \$70 million
- Environment and Health Outcome Tracking -- \$50 million
- Tuberculosis programs -- \$210 million
- Influenza preparedness -- \$157 million
- NIOSH -- significant and sustained increase

**National Institutes of Health**

**Significant and sustained increase with particular attention to lung disease  
at the following institutes and centers:**

- National Heart Lung and Blood Institute
- National Cancer Institute
- National Institute of Allergy and Infectious Diseases
- National Institute of Environmental Health Sciences
- National Institute of Nursing Research
- National Center on Minority Health and Health Disparities
- Fogarty International Center

**Statement of Albert A. Rizzo, MD,  
Speaker,  
American Lung Association Nationwide Assembly**

The American Lung Association is pleased to present our recommendations to the Labor, Health and Human Services, and Education Appropriations Subcommittee. The public health and research programs funded by this committee will prevent lung disease and improve and extend the lives of millions of Americans who suffer from lung disease.

The American Lung Association is the oldest voluntary health organizations in the United States, with national offices and local associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association today fights lung disease in all its forms through research, advocacy and education.

First and foremost, we want to thank you Mr. Chairman and this committee for the investments in health made in HR 1, the American Recovery and Reinvestment Act. The lung health community particularly appreciates the investments in research and funding for prevention and wellness programs.

**A SUSTAINED AND SUSTAINABLE INVESTMENT**

Mr. Chairman, the investments this committee makes can and will pay near term and long term dividends for the health of the American people and people everywhere.

- The reform of the health care system is an urgent national priority. Chronic disease is a huge driver of cost and human suffering. We urge the committee to focus resources on **reducing the burden of chronic disease.**
- America must maintain a renewed commitment to **medical research.** A growing, sustained, predictable and reliable investment in the National Institutes of Health provides hope for millions afflicted with lung disease and others. While our focus is on lung disease research, we strongly support increasing the investment in research across the entire National Institutes of Health.
- A new and sustained investment in **prevention and wellness** will lead to a healthier population and reduce health care costs. Investments in proven interventions like smoking cessation will reduce the burden of disease. The Centers for Disease Control and Prevention must be supported to drive this change.

Progress in these areas was made in FY2009 and in the stimulus bill but as you well know, Mr. Chairman, to see the outcomes that we all seek, these investments must be sustained over time.

**LUNG DISEASE**

Each year, more than 400,000 Americans die of lung disease. Lung disease is America's number three killer, responsible for one in every six deaths. More than 33 million Americans suffer from a chronic lung disease. Each year lung disease costs the economy an estimated \$154 billion. Lung diseases include: lung cancer, asthma, chronic obstructive pulmonary disease, tuberculosis,

pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

#### **IMPROVING PUBLIC HEALTH**

The American Lung Association strongly supports investments in the public health infrastructure. In order for the CDC to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs to improve the health of all Americans, we strongly support increasing the overall CDC funding to \$8.6 billion.

We strongly encourage improved disease surveillance and health tracking to better understand diseases like asthma. We support an appropriations level of \$50 million for the Environment and Health Outcome Tracking Network to allow federal, state and local agencies to track potential relationships between hazards in the environment and chronic disease rates.

We strongly support investments in communities to bring together key stakeholders to identify and improve policies and environmental factors influencing health in order to reduce the burden of chronic diseases. These programs lead to a wide range of improved health outcomes including reduced tobacco use. We strongly recommend at least \$30 million in funding for the Healthy Communities program to expand its reach to more communities.

#### **CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

Chronic Obstructive Pulmonary Disease, or COPD, is the fourth leading cause of death both in the U.S. and worldwide and the only leading cause of death that continues to increase. Yet, it remains relatively unknown to most Americans. COPD refers to a group of largely preventable diseases, including emphysema and chronic bronchitis that gradually limit the flow of air in the body. In 2007, the annual cost to the nation for COPD was \$42.6 billion. This includes \$26.7 billion in direct health care expenditures, \$8.0 billion in indirect morbidity costs and \$7.9 billion in indirect mortality costs. Medicare expenses for COPD beneficiaries were nearly 2.5 times that of the expenditures for all other patients.

Despite the enormity of this problem, COPD receives far too little attention at CDC or in health departments across the nation. The American Lung Association strongly supports the establishment of a national COPD program within CDC's National Center for Chronic Disease Prevention and Health Promotion with a funding level of at least \$1 million for FY 2010 to create a comprehensive national action plan for combating COPD. Creating this plan will address the public health role in prevention, treatment and management of this disease. This must occur if the nation is to begin to address this critical public health problem.

It has been estimated that 10.2 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2005, 127,049 people in the U.S. died of COPD. Women have exceeded men in the number of deaths attributable to COPD since 2000. Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Research on the genetic susceptibility underlying COPD is making progress. Research is also showing promise for reversing the damage to lung tissue caused by COPD. Despite these promising research leads, the American Lung Association

believes that research resources committed to COPD are not commensurate with the impact COPD has on the U.S. and the world.

The American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to COPD research programs. We strongly support a significant and sustained increase for the National Heart, Lung and Blood Institute budget and its lifesaving lung disease research program.

#### **LUNG CANCER**

An estimated 360,081 Americans are living with lung cancer. During 2008, an estimated 215,020 new cases of lung cancer were diagnosed, and 159,292 Americans died from lung cancer in 2005. Survival rates for lung cancer tend to be much lower than those of most other cancers. Men have higher rates of lung cancer incidence than women. However, over the past 32 years, the lung cancer age-adjusted incidence rate has decreased 15 percent in males compared to an increase of 150 percent in females. Further, African Americans are more likely to develop and die from lung cancer than persons of any other racial group.

Lung cancer receives far too little attention and focus. Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to lung cancer. We support a significant and sustained increase for the National Cancer Institute and urge more attention and focus on lung cancer.

#### **TOBACCO USE**

Tobacco use is the leading preventable cause of death in the United States, killing more than 443,000 people every year. Smoking is responsible for one in five U.S. deaths. The direct health care and lost productivity costs of tobacco-caused disease and disability are also staggering, an estimated \$193 billion each year.

Earlier this year, the Congress passed the extension of the Children's Health Insurance Program funded by a 62 cent increase in the tobacco tax. We commend Congress for passing this life saving legislation. In two weeks on April 1, the tax goes into effect. We know that increased prices encourage adults to quit and discourage kids from starting to smoke and even more must be done to help smokers quit and prevent kids from starting to smoke. We can prevent more than 80 percent of the cases of lung cancer and COPD by curbing tobacco use. Tobacco control must be priority one on the prevention and wellness agenda.

Given the magnitude of the tobacco-caused disease burden and how much of it can be prevented; the CDC Office on Smoking and Health should be much larger and better funded. Historically, Congress has failed to invest in tobacco control. This neglect cannot continue if the nation wants to prevent disease and promote wellness. The American Lung Association strongly supports a minimum level of at least \$160 million in FY 2010 funding for the Office on Smoking and Health. This represents a restoration, accounting for inflation, to the funding levels provided during the Clinton administration. We hope that the committee can provide significant and sustained growth to the Office on Smoking and Health.

**ASTHMA**

Asthma is a chronic lung disease in which the bronchial tubes become swollen and narrowed, preventing air from getting into or out of the lung. An estimated 34 million Americans have been diagnosed with asthma by a health professional. Approximately 22.9 million Americans currently have asthma, of which 12.3 million had an asthma attack in 2007. Asthma prevalence rates are over 38 percent higher among African Americans than whites. Studies also suggest that Puerto Ricans have higher asthma prevalence rates and age-adjusted death rates than all other racial and ethnic subgroups.

Asthma is expensive. Asthma incurs an estimated annual economic cost of \$19.7 billion to our nation. Asthma is the third leading cause of hospitalization among children under the age of 15. It is also one of the leading causes of school absences. The federal response to asthma has three components: research, programs and planning. We are making progress on all three fronts but more must be done:

***Asthma Research***

Researchers in the NHLBI-supported American Lung Association Asthma Clinical Research Network have discovered that asthma symptoms are not triggered in part by silent acid reflux. Therefore, the longstanding practice of prescribing heartburn medication to asthma patients who do not exhibit symptoms associated with acid reflux such as heartburn or stomach pain is ineffective and unnecessarily expensive. The results of this study, which has been accepted for publication in a prestigious journal, are considered to be the most comprehensive evaluation to date of the efficacy of prescription heartburn medication to control respiratory flare-ups in asthmatics whose symptoms have not been well controlled by other therapies. NIH should continue to invest in asthma clinical research trials like this one.

***Asthma Programs***

The American Lung Association recommends that CDC be provided \$70 million in FY10 to expand its asthma programs. This funding includes state asthma planning grants, which leverage small amounts of funding into more comprehensive state programs.

**INFLUENZA**

Influenza is a highly contagious viral infection and one of the most severe illnesses of the winter season. It is responsible for an average of 226,000 hospitalizations and 36,000 deaths each year. Further, the emerging threat of a pandemic influenza is looming. Public health experts warn that 209,000 Americans could die and 865,000 would be hospitalized if a moderate flu epidemic hits the U.S. To prepare for a potential pandemic, the American Lung Association supports funding the federal CDC Influenza efforts at \$157 million.

**TUBERCULOSIS**

Tuberculosis primarily affects the lungs but can also affect other parts of the body. There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2007, there were 13,299 cases of active TB reported in the U.S. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB pose a significant threat to the public health of our nation. Continued



support is needed if the U.S. is going to continue progress toward the elimination of TB. We request that Congress increase funding for tuberculosis programs to \$210 million for FY 2010.

#### **CONCLUSION**

The American Lung Association also would like to indicate our strong support for growth of additional institutes and programs that impact lung health. We strongly support a significant and sustained increase in funding for the NIH's National Institute of Allergy and Infectious Disease; particularly research on asthma, allergies and tuberculosis; National Institute of Environmental Health Sciences; to improve the understanding of impact of air pollution and other environmental factors on lung health; National Institute of Nursing Research and its research related to lung disease; National Center on Minority Health and Health Disparities and its research to reduce lung health disparities; the Fogarty International Center and its important work on tuberculosis; and CDC's National Institute for Occupational Safety and Health and its work related to occupational lung disease.

Mr. Chairman, lung disease is a continuing, growing problem in the United States. It is America's number three killer, responsible for one in six deaths. Progress against lung disease is not keeping pace with other major causes of death and more must be done. Mr. Chairman, the level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

**Albert A. Rizzo MD, FACP, FCCP**  
**Speaker of the Nationwide Assembly of the**  
**American Lung Association 2008-2009**  
**&**  
**Section Chief, Division of Pulmonary/Critical Care Medicine**  
**Christiana Care Health Systems Newark, DE**

Dr. Albert A. Rizzo is Chief of the Section of Pulmonary and Critical Care Medicine at the Christiana Care Health Systems in Newark, Delaware and is managing partner in a 13-physician pulmonary/critical care/sleep medicine group. He is board certified in internal medicine, pulmonary, and sleep medicine, and is a Clinical Assistant Professor of Medicine at Thomas Jefferson University Medical School in Philadelphia where he obtained his medical degree and completed his residency in Internal Medicine. He received his specialty training at Georgetown University Hospital in Washington, DC.

His private practice includes a strong interest in asthma, COPD, pulmonary rehabilitation, lung cancer and obstructive sleep apnea. Dr. Rizzo is medical director of a four site-18 bed sleep center. He is also Medical Director of the Lung Health and Sleep Enhancement Center which performs clinical research in pulmonary, critical care and sleep disorders.

Dr. Rizzo has been a volunteer with the American Lung Association since 1987 and is currently Speaker of the Nationwide Assembly of the American Lung Association, which is the body responsible for delivery of the American Lung Association's mission of research, advocacy, and education to promote lung health and prevent lung disease. Prior to being Speaker, he also chaired the Lung Association's Advocacy Committee, helped establish the American Lung Association Advocacy Day on Capitol Hill in 2007 and continues to be an active advocate for the Lung Association mission. The American Lung Association will be holding its third annual Day on the Hill on March 25, 2009.


**Financial Disclosures.** Dr. Rizzo is currently compensated as a promotional speaker for the following products: Astra-Zeneca (Symbicort), Novartis (Xolair), Boehringer-Ingelheim and Pfizer (Spiriva), Sepracor (Alvesco, Brovana, Xopenex). He and his practice currently are compensated for clinical research trials in the following disease states by Novartis (COPD), Actelion (Pulmonary Hypertension), and Gilead (Pulmonary Fibrosis). (Updated March 16, 2009)

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number: Albert A. Rizzo, MD Speaker, Nationwide Assembly American Lung Association 1301 Pennsylvania Avenue NW Suite 800 Washington DC 20004  202-785-3355											
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.  <p align="center"><b>American Lung Association</b></p>											
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?  <p align="center"><u>Yes</u>      No</p>											
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing. <b>American Lung Association</b> <table> <tr> <td>CDC: Asthma Friendly Schools Initiative</td> <td align="right">\$606,506</td> </tr> <tr> <td>CDC: Breathe Well, Live Well</td> <td align="right">\$290,000</td> </tr> <tr> <td>EPA: Comprehensive Childhood Asthma Management</td> <td align="right">\$1,200,000</td> </tr> <tr> <td>CDC: Asthma Policy Conference</td> <td align="right">\$60,000</td> </tr> <tr> <td>EPA: Controlling Cockroaches in Your Home Video</td> <td align="right">\$9,600</td> </tr> </table>		CDC: Asthma Friendly Schools Initiative	\$606,506	CDC: Breathe Well, Live Well	\$290,000	EPA: Comprehensive Childhood Asthma Management	\$1,200,000	CDC: Asthma Policy Conference	\$60,000	EPA: Controlling Cockroaches in Your Home Video	\$9,600
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EPA: Controlling Cockroaches in Your Home Video	\$9,600										

Signature: 

Date: March 16, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

WEDNESDAY, MARCH 18, 2009.

**OVARIAN CANCER NATIONAL ALLIANCE****WITNESS****SUSAN BUTLER**

Mr. OBEY. I regret to inform the Committee that I am told that we are going to have two votes sometime between 11:30 and 11:45, which will mess up the lives of the last three people on this list unless we can keep tightly to the time.

So, next, can we call Susan Butler?

Mr. Moran, I think you wanted to introduce her?

Mr. MORAN. Yes. Thanks, Mr. Chairman.

Susan, back in 1995, was diagnosed with ovarian cancer. At that time, the prospects were very harsh and the treatment options few. She was fortunate enough to enroll in an NIH clinical trial and it saved her life. Since then, she has devoted her life to the 22,000 additional women every year that are diagnosed with ovarian cancer, giving them hope and comfort.

I could go on and on—I will not—about the other things she does. She is a CEO; she has had award-winning websites; she has gotten the NIH Director's Award for her commitment to enhance patient care and service at NIH's Clinical Center.

But she is a great witness and thank you for having her, Mr. Chairman.

Mr. OBEY. Thank you.

Please proceed.

Ms. BUTLER. Mr. Chairman, Mr. Ranking Member, distinguished members of Congress, and especially Congressman Moran for your steadfast support of cancer and cancer research all of these years, I am Susan Lowell Butler, the Executive Director of the DC Cancer Consortium, and I am a proud cofounder of the Ovarian Cancer National Alliance, the national advocacy organization for ovarian cancer. As Congressman Moran has said, I am a 13-year survivor of simultaneous breast and ovarian cancer, and I am here today to ask you to fund programs in the Labor, HHS and Appropriations bill that will help combat this cancer.

In considering this request, please think of the sobering statistics of this cancer. About 22,000 women are diagnosed with ovarian cancer each year, and about 15,000 die from the disease. It is the fifth leading cause of cancer deaths among women, a statistic that has been unfortunately true for many years.

Fewer than 20 percent of women with ovarian cancer are diagnosed with early stages of the disease, where survival is the greatest, and only 45 percent of women diagnosed will live more than five years.

More than 70 percent of women who get the disease will have at least one recurrence; and when recurrence happens, within months after individual treatment, as is the case for many women, the cancer then responds to fewer and often less effective treatment options.

I am happy to say that, so far, despite the classic late diagnosis and the presence of another cancer, I have beaten the odds, and I

am pleased to be here more than 13 years after diagnosis and one year after a recurrence. I wish I had more company.

There are three major programs that address ovarian cancer in this bill that will help me have more company.

First is Johanna's Law: The Gynecologic Cancer Education and Awareness Act. Many of you have been vocal champions for this bill and I thank you for your work. The program has been funded for the past two years, allowing the Centers for Disease Control to begin a national awareness campaign about the signs and symptoms of gynecologic cancer.

The law is named for Johanna Silver Gordon, who, like many women, had symptoms of ovarian cancer that she missed, as did her health care providers. Without a reliable early detection screen, our best hope now is for early detection is awareness among women and their health care providers of the signs and symptoms of the ovarian cancer. On behalf of the thousands of women that experience these symptoms, we ask that you appropriate \$10,000,000 for this program for fiscal year 2010.

But symptom awareness is just the beginning. We need better treatments for women who have the cancer, as well as a real understanding of how it works in the body. We do not know enough about who is at risk, how this disease develops, how to detect it early, and how to keep it in remission. Other than that, we are in good shape. Without sufficient basic and translational research, we will never have that knowledge.

The National Cancer Institute funds SPORÉ programs, Specialized Programs of Research Excellence, which are cross-institutional research programs and an important research collaboration. One of these SPORÉs is run by the Gynecologic Oncology Group, which runs many much needed clinical trials on ovarian cancer. In fiscal year 2008, NCI funded more than 500 research grants on ovarian cancer across a wide array of important issues. Please keep this critical research going and increase the appropriations for NCI to \$6,000,000,000 for fiscal year 2010.

Finally, CDC runs the Ovarian Cancer Control Initiative, a research program that includes risk perception and screening for women at high risk, clinical practices in the follow up of ovarian masses, and in the relationship between symptoms and time to diagnosis. This research is of critical importance, and on behalf of the women and families who are touched by or at risk of being touched by ovarian cancer, we request you increase its funds to \$10,000,000.

Despite these grim statistics, the research you have funded over the years has brought progress and years of life for women with ovarian cancer. On behalf of all of us, thank you for what you have done and we hope very much for your continued support in the future. I will take any questions you may have.

[The information follows:]



Public Witness Testimony of  
 Susan Lowell Butler,  
 Executive Director, DC Cancer Consortium,  
 Founding Member of Ovarian Cancer National Alliance  
 on behalf of  
 Ovarian Cancer National Alliance

Mr. Chairman, Mr. Ranking Member, and distinguished Members of Congress, good morning, and thank you for inviting me to testify today.

I am Susan Lowell Butler, the executive director of the DC Cancer Consortium. I am also a co-founder of the Ovarian Cancer National Alliance, the national advocacy organization for ovarian cancer. I am a thirteen-year survivor of simultaneous breast and ovarian cancer - and I am here today to ask you to fund programs in the Labor-HHS and Education Appropriations Bill that will help combat ovarian cancer.

In considering this request, please consider the sobering statistics of this disease:

- Approximately 22,000 women were diagnosed with ovarian cancer each year – and about 15,000 women die annually from the disease. It is the fifth leading cause of cancer deaths among women – a statistic that has been true for many years;
- Fewer than 20 percent of women with ovarian cancer are diagnosed in the early stages of the disease, when survival is greatest. Only 45 percent of women diagnosed will survive more than five years;
- More than 70 percent of women will have at least one recurrence;
- When a recurrence happens within months after initial treatment, as is the case for many women, the cancer then responds to fewer and often less effective treatment options.

I am happy to say that so far, despite late diagnosis and the presence of another cancer, I have beaten the odds, and am pleased to be here more than 13 years after my diagnosis and one year after a recurrence. I wish I had more company.

There are three major programs that address ovarian cancer in this bill.

First is Johanna's Law: The Gynecologic Cancer Education and Awareness Act. Many of you have been vocal champions for this bill, and I thank you for your work. This program has been funded for the past two years, allowing the Centers for Disease Control and Prevention to begin a national awareness campaign about the signs and symptoms of gynecologic cancers. The law is named for Johanna Silver Gordon, who, like many women, had symptoms of ovarian

cancer which were missed by both her and her healthcare provider. Without a reliable early detection screen, our best hope for early detection is awareness among women and their health care providers of the signs and symptoms of ovarian cancer. On behalf of the thousands of women that experience symptoms of ovarian cancer, we ask that you appropriate \$10 million for this program for FY 2010.

But symptom awareness is just the beginning. We need better treatments for women who have this cancer, as well as real understanding of how it works in the body. We don't know enough about who's at risk, how this disease develops, how to detect it early, and how to keep it in remission. Without sufficient basic and translational research, we never will.

The NCI funds SPORE programs - Specialized Programs of Research Excellence - which are cross - institutional research programs – an important research collaboration. One of the SPOREs is run by the Gynecologic Oncology Group, which runs much-needed clinical trials on ovarian cancer. In Fiscal Year 2008, the NCI funded more than 500 research grants on ovarian cancer across a wide array of important issues. Keep this critical research going – and increase appropriations for the National Cancer Institute to \$6 billion for FY 2010.

Finally, the CDC runs the Ovarian Cancer Control Initiative, a research program that includes risk perception and screening for women at high risk for ovarian cancer; clinical practices in the follow up of ovarian masses; the relationship between symptoms and time to diagnosis; and tracking both incidence and surgical interventions of ovarian cancer. This research is of critical importance, and on behalf of the women and families who are touched by, or at risk of being touched by, ovarian cancer we request that you increase its funds to \$10 million for FY 2010.

Despite the grim statistics, the research you have funded over the years has brought progress for women with ovarian cancer. When I was diagnosed in 1995, the treatment options were relatively few, and harsh. Nonetheless, the clinical trial I was on at NCI saved my life. The good news is that today's first-line treatment allows most women to participate more fully in their lives throughout it – an immeasurable gift, I assure you. So on behalf of the entire ovarian cancer community – patients, family members, clinicians and researchers – we thank you for your leadership and support of federal programs that seek to reduce and prevent suffering from ovarian cancer. Thank you in advance for your support of these programs.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

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<p>Your Name, Business Address, and Telephone Number:</p> <p><b>Susan Lowell Butler, Executive Director DC Cancer Consortium 4125 Albemarle St NW Washington, DC 20016 303-895-9445</b></p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p><b>On behalf of the Ovarian Cancer National Alliance, a non-governmental organization</b></p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?</p> <p>Yes <input type="radio"/> No <input checked="" type="radio"/></p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p>

Signature: *Susan Lowell Butler* Date: 3-14-09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.



WEDNESDAY, MARCH 18, 2009.

**AMERICAN SOCIETY OF CLINICAL ONCOLOGY**

**WITNESS**

**RICHARD L. SCHILSKY, M.D.**

Mr. OBEY. Next, American Society of Clinical Oncology, Dr. Richard Schilsky.

I am going to ask people to please hold it to four minutes so that we do get to hear everybody before the bells mess us up.

Go ahead.

Dr. SCHILSKY. Good morning, Chairman Obey, Ranking Member Tiahrt, members of the Subcommittee. Thank you for the opportunity to testify today. My name is Richard Schilsky. I am a medical oncologist at the University of Chicago and President of the American Society of Clinical Oncology. On behalf of ASCO's 27,000 members who treat people with cancer and conduct oncology research, I want to thank you first for your longstanding commitment to cancer research and highlight the critical importance of sustaining a robust and vibrant national clinical trial system through NIH and NCI.

My testimony today will focus on the following points: We thank Congress and the President for the recent stimulus funding for NIH that will help cancer patients and provide significant boost to our local economies. We urge the Subcommittee to support the President's fiscal year 2010 budget proposal for NIH and a sustained multi-year commitment to increasing funding for cancer research.

This Federal funding for cancer research is critical for a number of reasons, including to advance the best interest of U.S. patients, to support our next generation of cancer researchers, and to answer important questions about cancer diagnosis and treatment.

ASCO applauds President Obama's call to cure cancer, and we strongly support the President's request of over \$6,000,000,000 for cancer research within NIH and, importantly, his pledge to provide a multi-year plan to double Federal funding for cancer research. We believe that most of this funding should support work carried out through the extensive NCI network.

This Country is poised to deliver on the challenge to cure cancer. Cancer deaths are decreasing and the survival rates for many cancers are increasing. These successes are largely the result of our publicly funded research system. However, the underlying research infrastructure is at a critical break point, endangered by a lack of predictable funding and the failure to keep pace with the growing costs of conducting research.

We commend Congress for the additional \$10,400,000,000 for NIH included in the stimulus bill. However, this funding has some limitations: it cannot fund multi-year research or stave off the impact of the 15 percent decline in purchasing power that NIH has lost since 2003. Only sustained funding into NIH and NCI's baseline can ensure the long-term viability of the U.S. research system.

Sustained funding will also bolster our researcher workforce, our next generation of investigators, one of the most important resources to preserve our position as the world leader in medical in-

novation. These young people are questioning whether to pursue careers as clinician investigators. Most importantly, lack of adequate funding threatens the important trials being performed through NCI that provide access to innovative therapies for Americans in virtually every community where cancer care exists.

Federally funded research answers questions that are fundamentally different from the studies that typically are supported by private companies. Federally funded research answers important questions regarding cancer diagnostics and treatments that improve patient care. As one example that reflects the movement toward personalized medicine, we now know that 40 percent of colon cancer patients have tumor with a particular gene mutation that makes certain drug treatments ineffective. By testing each patient with a colon tumor, we can customize their treatment regimens and care plans. Such research, while resource-intensive, promotes better outcomes for patients, avoids unnecessary treatments, and results in savings for our health care system.

Thank you for the opportunity to present ASCO's views to the Subcommittee today. We look forward to continuing our long-standing collaborative work with you to provide improved clinical outcomes for all Americans who are faced with cancer. Thank you.

Mr. OBEY. Thank you.

[The information follows:]

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**Testimony of**

**Richard L. Schilsky, M.D.**

**President, American Society of Clinical Oncology**

**Before the Subcommittee on Labor, Health and Human Services,  
Education & Related Agencies**

**House of Representatives Committee on Appropriations**

**March 18, 2009**

**10:00 am**



American Society of Clinical Oncology

Thank you for the opportunity to submit testimony before the Labor, Health and Human Services, Education and Related Agencies Subcommittee today. My name is Richard Schilsky, M.D. I am a medical oncologist at the University of Chicago and President of the American Society of Clinical Oncology (ASCO).

ASCO is the leading specialty society in the United States and throughout the world for physicians who treat people with cancer and conduct oncology research that leads to improved patient outcomes. ASCO is committed to ensuring that high quality, evidence-based practices for the prevention, diagnosis and treatment of cancer are available to all Americans in every community throughout the United States. To this end, on behalf of our 27,000 members, I wish to highlight the critical importance of sustaining a robust and vibrant national clinical trials system through the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

ASCO has a long history of working collaboratively with federal policy makers and physicians in communities throughout the United States to promote the best interests of patients with cancer and to advance scientific discovery. ASCO also works to translate scientific developments into clinical guidelines to help inform the treatment decisions made by physicians and their patients.

My testimony will focus on the following points:

- ASCO commends Congress and President Obama for the steps you have taken to enhance funding for biomedical research. These efforts will serve the overarching goal of leading to scientific advancements that improve the outcomes for cancer patients while providing rapid assistance to local economies throughout the United States by putting talented research professionals to work. Every dollar of NIH support returns at least \$2.50 in economic growth to the local community.
- ASCO urges the Subcommittee to support the President's budget request for NIH and NCI for FY2010 and urges a sustained, multi-year commitment to increasing the levels of funding for cancer research through NIH and NCI.
- Federal funding for cancer research plays a critical role in advancing the best interests of patients and complements the research investment made by U.S. companies by addressing different scientific questions.
- Federal funding is needed to support research conducted within the United States, providing U. S. patients with access to innovative therapies and answering scientific questions in diverse patient populations within the U.S. health care system.

- To maintain the United States' leadership in innovation, federal funding is needed to support our next generation of cancer investigators.

## Discussion

### 1. ASCO commends Congress and President Obama for the steps you have taken to enhance funding for biomedical research.

President Obama boldly called for a cure to cancer in his recent address to a joint session of Congress. We applaud him for this leadership and support his budget proposal request of over \$6 billion dollars for cancer research within NIH and his pledge to provide a sustained, multi-year plan to double funding for cancer research. NCI directs the majority of our federal cancer research activities. Most of the funding set aside for cancer research in the President's budget should support work carried out by the NCI's extramural and intramural activities, but there are also opportunities for critical collaborations with other departments and agencies, both within NIH and across the federal government, and with the broader cancer research community throughout the private sector. The President's budget is also consistent with NCI's professional judgment budget, reflecting the scientific opportunities that we could realize in the next fiscal year with adequate funding.

This country is remarkably poised to deliver on the President's challenge. Over the last 50 years, this nation has developed the world's preeminent cancer clinical trials system through its cancer centers, Cooperative Groups, Community Clinical Oncology Program, Specialized Programs or Research Excellence (SPOREs), and other mechanisms. This publicly-funded system has brought great progress in cancer prevention and treatment and has leveraged billions of dollars in philanthropic investment and commercial partnership. The number of cancer deaths has decreased for the first time in 70 years, despite a growing and aging population. Survival rates for many of the most common cancers – including breast, colon, and prostate – are rising. In fact, there are now 12 million American cancer survivors, up from 3.7 million 30 years ago. Treatments are becoming more targeted and less toxic, and we are entering an era of personalized therapies, in which treatment will be increasingly tailored to the genetic profile of an individual tumor. But the people necessary to do the work and the underlying infrastructure are at critical break points, and have been endangered by a failure to keep pace with the growing costs of conducting research and a lack of predictable funding for NIH and NCI since 2003.

The additional \$10.4 billion dollars for NIH included in the American Recovery and Reinvestment Act of 2009 presents a tremendous opportunity for biomedical and cancer research. We applaud Congress for providing this significant investment as part of the economic stimulus effort. This will allow for support of ROIs, Challenge Grants, and other research grants that have a reasonable expectation of making progress in two years, as well as administrative and competitive supplements to current grants. NCI is quickly dispersing the stimulus funds to communities throughout the U.S through its existing matrix of extramural programs. The economic benefit of this infusion will be quickly realized through the hiring of research personnel and purchasing of state-of-the-art equipment necessary to energize the entire research

enterprise. It will translate directly to increased job opportunities for young investigators, research nurses and research staff.

**2. ASCO urges the Subcommittee to support the President's budget request for FY2010 appropriations and urges a sustained, multi-year commitment to increasing the levels of funding for cancer research through NIH and NCI.**

The stimulus funding for biomedical research has limitations. Unfortunately, the stimulus funding will not stave off the impact of lost purchasing power in the underlying budgets for NIH and NCI – NIH has lost 15 percent of its purchasing power since 2003. This will not be recovered unless Congress puts additional funding into NIH and NCI's baseline. The results of this stagnant funding have been far reaching. Researchers are abandoning or avoiding cutting-edge projects that may be less likely to be funded. Senior investigators report that many of the brightest young minds in our country no longer see the promise of a career in science, choosing other careers instead. Investigators are spending more of their time seeking funding – time that could be spent conducting research in the laboratory or treating patients in the clinic. Clinical trials are being delayed or discontinued and patient enrollment in the United States is flagging. These losses have delayed the quest for new cures, demoralized the research workforce, and left us with few options to buttress a starving infrastructure that can no longer rely on clinical margins to counterbalance inadequacies in research dollars.

The stimulus funding will not help ensure the long-term viability of our research system. Clinical research does not take place without physician investigators, research nurses, pharmacists, clinical research coordinators, data managers, and research administrators to interact with patients and gather clinical trials data. Lapses in funding jeopardize our ability to keep these people in place, ensure their training and attract a future workforce.

Yearly increases that keep pace with inflation are also necessary to ensure we can invest in the clinical trials that are necessary to transform laboratory findings into diagnostics and therapeutics that will improve patient care. While we would like the process to be quicker, the reality is that clinical trials are multi-year projects from conception to implementation to completion and analysis. This is especially true in cancer where we do not yet have many alternatives to demonstrate effectiveness other than the impact on survival rates or other surrogate endpoints such as time to progression. Because of the nature of the therapies we are testing, we also have to follow patients for extended periods after the clinical trial has closed to ensure we understand the long-term effects that may jeopardize the quality of life for cancer survivors. Ultimately, sustained annual research funding will increase physician and patient participation in clinical trials, which will help accelerate the development of new cancer diagnostics and treatments.

**3. A federally-funded system for cancer research plays a critical role in advancing the best interests of patients.**

It is critical that the United States preserve a vibrant federally-funded clinical trials system as a complement to the trials performed by private entities. While manufacturers are often effective at bringing a new treatment to market, it is federally-funded research – particularly in the case of cancer – that ultimately helps us understand how to best use cancer treatments to treat patients.

Federally-funded trials answer comparative effectiveness questions by comparing one treatment directly to another. By independently and objectively comparing available therapies, we can determine who will benefit, who will not, and in doing so, avoid the cost of treatments that are unlikely to be effective for specific patients. Federally-funded trials develop biospecimen repositories that enable the development of molecular tests to predict prognosis and response to treatment. Federally-funded researchers also are often the only ones able to focus on diseases in small populations and in children. The trials conducted to gain initial approval are often done in patients with advanced disease. NCI-funded research has helped us understand how to use drugs in multiple disease settings and for patients with earlier stages of disease where the potential benefits are much greater.

**4. Federal funding for cancer research is needed to support research conducted in all settings within the United States.**

We are moving into the frontier of personalized medicine, beginning to treat patients not just by the site of their tumor but by the genetic composition of their disease and of their normal DNA. This enables us to determine which patients will benefit from a treatment, and just as importantly, which patients will *not* benefit from a treatment. These are questions that industry might not be willing to fund. Research presented at last year's ASCO meeting demonstrated that, for colon cancer patients whose tumors possess a particular mutation of the gene, KRAS, certain drug treatments will not be effective. Based on this data, ASCO now recommends that all patients with metastatic colorectal cancer be tested for the KRAS gene mutation and that those who possess it not be treated with these drugs. These research results not only allow better outcomes for patients and avoidance of unnecessary treatment, but result in enormous savings for our health care system.

While the private sector plays an important role in the development of new therapeutic options, there is also concern that many industry-funded trials are increasingly conducted overseas. There are several reasons for this development, but the long-term result may be that trial results may be inadequate to guide U.S. clinicians seeking to prescribe the treatments to U.S. patients. In addition, U.S. researchers will participate less in the discovery process, and our country will lose this vital portion of the economy. More troubling is the fact that U.S. patients will have less access to state-of-the-art treatment options. A robust federal research infrastructure will help protect against this brain drain and loss of options for patients.

We have made important strides in ensuring that clinical studies are performed at the community level, providing patients with access to innovative therapies and answering scientific questions in diverse patient populations – but more needs to be done.

Improvements in anti-cancer and supportive care treatments enable us to offer treatments to 85 percent of cancer patients in their communities and near their homes. NCI has followed this with development of a robust extramural mechanism that funds access to its trials throughout the U.S. in virtually every community in which cancer care is offered. Non-academic, community sites accrue at least 50 percent of the patients participating in the Cooperative Group system – which conducts the majority of NCI-funded clinical trials (25,000-30,000 patients per year). The Community Clinical Oncology Program also brings cancer prevention trials into the community

setting, and the Minority-based Community Clinical Oncology Program enrolls 60 percent minority patients. Investigators participate in this research because it addresses important scientific questions and to provide a full range of treatment options to their patients. However, the funding the federal government provides to enable this participation only covers one-third of the actual research costs. It is vital that a portion of the FY2010 budget be dedicated to addressing this disparity.

**5. To maintain the United States' leadership in innovation, federal funding is needed to support the next generation cancer investigators.**

NIH provides critical funds to our training institutions to ensure that we are continually developing our next generation of investigators. The economic environment is making it increasingly difficult for these institutions to continue this vital mission. Coupled with the growing concern about whether we will have an adequate workforce in the coming years, this is making trainees reconsider pursuing a career as a clinician investigator. Increasing funds in this area would help ensure that we continue to bring the best minds to the field of translational and clinical research.

If Congress chooses to provide over \$6 billion for cancer research at the NIH, the benefits will not accrue to cancer patients alone. Cancer research is a paradigm for other diseases. Therapeutic breakthroughs in cancer research have led to treatments for many other diseases, including rheumatoid arthritis and macular degeneration.

Thank you for the opportunity to present ASCO's views on appropriations to the Subcommittee today. We look forward to working with you to ensure a vibrant federally-funded clinical trials system for people with cancer. Only by rapidly translating basic science discovery into clinical application and ensuring widespread access to life-saving treatment will we continue to improve the outcomes for all Americans with cancer.



**Richard L. Schilsky, MD**  
**ASCO President, 2008-2009**

Dr. Schilsky, a medical oncologist, is Professor of Medicine at the University of Chicago. Since 1995, he has served as Chair of Cancer and Leukemia Group B, presiding over a national research network that conducts clinical trials in cancer treatment, biology, prevention and health outcomes. Dr. Schilsky's research focus is gastrointestinal cancers and cancer pharmacology and drug development, and his research has been continuously funded by the National Cancer Institute (NCI) since 1987.

An ASCO member since 1980, Dr. Schilsky has served the Society in many capacities. He served on the Board of Directors from 2002–2005, functioning as Board liaison to the Grants Selection Committee, a member and Chair of the Personnel Committee, and a member of the Executive Committee. Dr. Schilsky was the Scientific Program Committee Chair in 2005 and a member of the Steering Committee for the Gastrointestinal Cancers Symposium in 2006. He is a current member of the ASCO Government Relations Council and Chair of the Cancer Research Committee. He has also served on the Clinical Trials Task Force and the Selection Committee for the Advanced Clinical Research Award in Breast Cancer. He was on the *Journal of Clinical Oncology* Editorial Board from 1990 to 1993.

Dr. Schilsky is an active member of AACR, the European Society for Medical Oncology, the American Society for Clinical Pharmacology and Therapeutics, the American College of Physicians, the American Association for Cancer Education, the International Society of Geriatric Oncology, the Association for Patient-oriented Research, and the Society for Clinical Trials. He has been a member of the NCI Board of Scientific Advisors since 1999, was recently appointed to the Clinical Trials Advisory Committee, and has served on numerous peer review and advisory committees. He has been a member and Chair of the Oncologic Drugs Advisory Committee of the U.S. Food and Drug Administration.

Dr. Schilsky is an Associate Editor of *Clinical Cancer Research* and on the Editorial Board of *Molecular Oncology*, *Seminars in Oncology*, the *Journal of Cancer Research and Clinical Oncology*, *Clinical Advances in Hematology & Oncology*, *The Oncologist*, and *CURE*. He has published more than 240 articles and book chapters and is the editor of four books.

Dr. Schilsky earned a medical degree with honors from the University of Chicago Pritzker School of Medicine. Following a residency in internal medicine at the University of Texas Southwestern Medical Center and Parkland Memorial Hospital, he received training in medical oncology and clinical pharmacology at the NCI.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

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Your Name, Business Address, and Telephone Number:

Richard L. Schilsky  
Professor of Medicine  
Biological Sciences Division, University of Chicago  
5841 S. Maryland Avenue, MC 2115  
Chicago, IL 60637  
773-834-3914

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

American Society of Clinical Oncology, Inc.

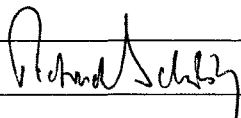
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes ☒ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

The organization Dr. Schilsky is representing, American Society of Clinical Oncology, Inc., has not received federal grants or contracts during this period. Dr. Schilsky is Chair of the Cancer and Leukemia Group B (CALGB), which receives federal funding for medical research. NIH grants to CALGB for research on which Dr. Schilsky is principal investigator are listed on the attached page.

Signature: \_\_\_\_\_



Date: \_\_\_\_\_

3/17/09

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**RESEARCH SUPPORT RECEIVED BY CALGB FROM THE NIH/NCI FOR WHICH  
DR. SCHILSKY IS PRINCIPAL INVESTIGATOR**

**1. Central Operations grant for the cooperative group**

5 U10 CA31946-27	9/30/83 - 3/31/09	6.00 Calendar
	\$9,482,300	

**2. CALGB Human Specimen Repositories**

5 U24 CA114725-04 (Schilsky)	6/6/05 – 3/31/10	.12 Calendar
	\$1,851,664	

To establish a national tissue-banking program, which will sustain the core operations of the CALGB specimen repositories including specimen collection, storage, quality control, distribution, inventory management, security and confidentiality.

**3. CALGB Research Base Community Clinical Oncology Program**

5 U10 CA37447-25 (Schilsky)	9/30/83 – 5/31/09	1.20 Calendar
	\$1,550,073	

The major goal is to act as a research base for the CALGB Community Clinical Oncology Program.

WEDNESDAY, MARCH 18, 2009.

**ASSOCIATION FOR CLINICAL RESEARCH TRAINING**

**WITNESS**

**HARRY P. SELKER, M.D.**

Mr. OBEY. Next, Dr. Harry Selker, Association for Clinical Research Training.

Dr. SELKER. Thank you for inviting me here today. My name is Dr. Harry Selker. I am past President and current Chair of the Advocacy and Public Policy Committee for the Association for Clinical Research Training, ACRT.

ACRT is committed to improving the Nation's health by increasing the amount and quality of clinical research through the expansion and improvement of clinical research training. We also serve as a host organization for the National Alliance for Societies for Clinical Research Resources that coalesces in support of these goals.

I want to start by thanking the Subcommittee for its strong commitment to improving health through the recently passed fiscal year 2006 Omnibus Appropriations package and the economic stimulus legislation. Both bills provided meaningful funding increases for our Nation's health sciences agencies, specifically National Institutes of Health and Agency for Healthcare Research and Quality. These will translate into improved treatments and health for our citizens.

I want to address three issues that are critical to optimally leveraging the Country's investment in research and health care. To not address these is to not take advantage of the world's greatest biomedical research and medical care capabilities just when we need to.

First, I want to talk about the importance of fully funding the NIH Clinical and Translational Science Awards, the CTSAs. In 2005, NIH announced an ambitious plan to create CTSAs at 60 universities, with the goal of transforming our Nation's biomedical research enterprise and become more effectively translational into improved health care. This is a major undertaking for NIH, but with the understanding that it will repay that investment many times over.

Funding started for the first 12 CTSAs in 2006 with great promise; however, with increasingly constrained resources at NIH, NIH's National Center for Research Resources that administers the CTSAs and the Office of the Director curtailed CTSA funding. Thus, for the CTSAs started in 2007 and in 2008, upon funding, there were deep cuts, sometimes exceeding 50 percent of their budgets, as they had constructed them based on the RFA.

Now, with improvements at NIH funding brought by the stimulus package and the fiscal year 2009 appropriations, NIH and NCCR could potentially restore full funding for the current 38 CTSAs going forward, but it is concerned about doing so because of the long-term commitment that would be needed for full funding of their goal of 60 fully-funded CTSAs. This deserves the attention and support of this Subcommittee.

Second, I would like to bring to your attention the importance of restoring and growing K-Awards and T-32 awards for research, training, and career development. Last year, the Subcommittee showed strong leadership and urged NCCR to continue K-30 Clinical Research Curriculum Awards to support core needs in research training and career development at those institutions that do not have CTSA. I am pleased to inform you that NCCR has complied with this request and recently issued the K-30 re-competition announcement.

However, these K-30 awards support the curriculum to train the needed new generation of clinical and translational researchers, but they do not have funds for stipends or the tuition for the young physician investigators to actually take the courses. Thus, to leverage this growing capacity for training, there is a need to grow at NIH and AHRQ—not cut back, as they have done recently—K series research career development awards and T-32 training awards so that young researchers can participate in these K-30 and CTSA training programs.

Third, and lastly, I want to emphasize the importance of continuing your support for Comparative Effectiveness Research, CER. The American Recovery and Reinvestment Act of 2009 contained \$1,100,000,000 for CER activities, as was mentioned, at NIH and AHRQ. AHRQ has been the Federal focus for CER, especially since the Medicare Modernization Act, and NIH has been supporting CER for some time. We are pleased that Congress recognizes the importance of this work and that CER's proper home is in the health sciences agencies, where peer review process and infrastructure are in place to ensure the highest quality science, rather than at a new, untested funding entity.

Thank you for this opportunity to share my views with you.

Mr. OBEY. Thank you.

[The information follows:]



**ASSOCIATION FOR CLINICAL RESEARCH TRAINING**

**Statement of  
Harry P. Selker, MD, MSPH  
Dean, Tufts Clinical and Translational Science Institute  
Executive Director, Institute for Clinical Research and Health Policy Studies  
Tufts University and Tufts Medical Center, Boston, MA**

**On Behalf of  
Association for Clinical Research Training  
Past President and Chair, Advocacy Committee  
1500 Sunday Drive, Suite 102  
Raleigh, NC 27607**

**A Member Organization of the National Alliance of Societies for Clinical Research  
Resources (NASCRR):**

***American Federation for Medical Research (AFMR), Association for Clinical  
Research Training (ACRT), Association for Patient-Oriented Research (APOR),  
Clinical Research Forum (CR Forum), Society for Clinical and Translational Science  
(SCTS), and Society of General Internal Medicine (SGIM)***

**Regarding Fiscal Year 2010 Appropriations for Clinical Research Training**

**Submitted to the  
House Committee on Appropriations; Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies**

**Wednesday, March 18, 2009, 10:00AM**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2010:**

- 1) Works towards fully funding the emerging Clinical and Translational  
Science Awards (CTSA) Program by providing \$573 million in support.**
- 2) Continued support for the NIH and AHRQ K-Awards for the training and  
career development of research scientists.**
- 3) Continued emphasis on the importance of Comparative Effectiveness  
Research (CER) conducting at NIH and the Agency for Healthcare Research  
and Quality (AHRQ).**

ACRT is committed to improving the nation's health by increasing the amount and quality of clinical research through the expansion and improvement of clinical research training. This training and related career development support comes largely from funds from the NIH and AHRQ.

NASCRR is comprised of the national organizations that provide leadership in the field of clinical and translational research and training. NASCRR coalesces around areas of common concern for the entire biomedical research and training communities and works in support of these goals.

I want to start by thanking the Subcommittee for its strong commitment to improving public health through the recently passed FY 2009 Omnibus Appropriations package and economic stimulus legislation. Both bills provided meaningful funding increases to agencies such as NIH and AHRQ that will translate to improved treatments and health for our citizens. ACRT and NASCRR applaud the Subcommittee for its role in securing this funding, and we hope that this commitment can be sustained and enhanced in subsequent years that should translate into better treatments, healthcare, and health for the US public.

I want to address three issues that are at the center of biomedical research today. First, as is now appreciated by Federal health sciences agencies, Congress, and the new Administration, to gain maximal impact from the nation's investment in biomedical research, there must be a concerted focus on research that translates biomedical science results into improved treatments and more effective healthcare. Second, the past few years have not provided the career development opportunities to generate sufficient well-trained researchers able to do this crucial work. Third, in order to translate the best research results into excellent healthcare, there has to be research that compares the effectiveness of different treatments and for different patients. These three needs are crucial to optimally leveraging the country's investment in research and in healthcare; to not facilitate these is to not to take advantage of the world's greatest biomedical research and medical care capabilities at just a time when we need them.

#### **1) The importance of fully funding the CTSA program.**

In the past several years, researchers, the healthcare system, and NIH have come to realize the great need for research focused on translational research – translation from the laboratory bench to the bedside for testing in humans, translation from the patient bedside at major academic health center research units to widespread medical practice, and translation from widespread practice into improvements in the public's health, healthcare, and health policies. In 2005, NIH announced an ambitious plan to create CTSAs at 60 universities, with the explicit goal of transforming the entire biomedical research enterprise to become more effectively translational in these ways, with the explicit goal of improved healthcare in this country. This has been a major undertaking and investment for NIH, but with the understanding that better treatments, better health, and growth in biotechnology industry will repay this many times over. The specific goals of NIH for the CTSA program are: 1) improving the way biomedical research is conducted across the country; 2) reducing the time it takes for laboratory discoveries to become treatments for patients; 3) engaging communities in clinical research efforts; and 4) training and developing the careers of the next generation of clinical and translational researchers.

Significant resources were promised to the research community in the form of major grants that provide the needed infrastructure, resources, education, and career development support to transform (see Zerhouni, E. Translational and Clinical Science —

Time for a New Vision. *New England Journal of Medicine*, 353:14, October 12, 2005), with the plan to roll-out 60 CTSA programs nationally over five years. This started with the funding of 12 CTSA programs in 2006, with enormous attention and great promise by the U.S. and international scientific communities. However, soon, with the years of near-level funding of NIH had drained the pool of resources that could be committed to supporting the growing CTSA network. Because of this, the NIH National Center for Research Resources (NCRR), that administers CTSA programs, and the NIH Office of the Director, had to curtail support for CTSA programs. By the time the funding of the second group of 12 CTSA programs in 2007, and also for third group of 14, funded in 2008, the budgets that applying universities had constructed based on the original request for applications, which had been approved by the review process, were cut, in some cases by more than 50%. The proposals were peer-reviewed in an extremely competitive pool, and those funded were those deemed most meritorious based on their planned budgets. Nonetheless, the great promise of the CTSA programs fell to the same axe that was causing funding difficulties throughout NIH.

Now, with the improvements in NIH funding brought by the stimulus package and the FY09 Appropriations, NCRR/NIH could potentially restart full funding of the current 38 CTSA programs, but there remains concern about making such a commitment due to the long term commitment this would require for full funding of the goal of 60 fully-funded CTSA programs. This deserves the attention and support of the Subcommittee.

In fact, the current situation is frustrating for current and prospective CTSA institutions. We applaud the funding for NIH, NCRR, and comparative effectiveness research (CER) that was provided through the economic stimulus package, and this would seemingly provide a start to repair the shortfall for CTSA programs. However, presently, NCRR and other NIH Institutes and Centers are holding competitions and accepting proposals that will be reviewed in the coming months to allocate the stimulus funds. Many of the research activities which are being proposed are similar to activities the CTSA programs already planned in their initial peer-reviewed applications, but have been unable to undertake due to a lack of funding. It makes more sense to us that this funding be allocated immediately to meritorious proposals made by CTSA recipients that have already been peer-reviewed and are therefore ready to be implemented right away. By doing so, NIH can fulfill the commitment to fully-supporting the CTSA program, and more immediately enable the impact of the economic stimulus legislation.

We fully understand that funding for the CTSA program over the long term will require sufficient appropriations on an annual basis. The CTSA program is currently funded at approximately \$475 million. You will note from the attached professional judgment budget prepared by NCRR in December that to facilitate appropriate implementation the program should be funded at \$573 million in FY 2010. Additionally, this document shows that to fully implement the program and support a network of 60 centers by 2011, a funding level of approximately \$672 million is required.

*It is our recommendation that the Subcommittee support full implementation of the CTSA program by providing \$573 million in FY 2010 and \$672 million of support in FY 2011, and by encouraging NIH to continue to build the program to 60 CTSA programs.*

## **2) The importance of continuing to support the K-Award research training and career development programs**



As the CTSA program is rolled out, it is subsuming the activities of other NCRR programs, such as the K-30 Clinical Research Curriculum Awards (CRCA) that provides the curricular support for the development of badly needed graduate programs in clinical and translational research. However, while flat budgets slowed implementation of the CTSA network, the phasing out of K-30 awards continued on unimpeded. Last year the Subcommittee showed strong leadership and urged NCRR to continue the CRCA program for those institutions that had not yet received a CTSA. I am pleased to inform you that the NCRR has complied with this request, and recently the Center issued the K-30 re-competition notice. Thank you for taking an interest in clinical research training and please continue to do so moving forward!

These K-30 awards (and CTSA, where these are in place) provide the curriculum to train the needed new generation of clinical and translational researchers, but they do not have funds to pay stipends or tuition for young physician-investigators to take these courses, nor does it supply the career development support for incorporating such an education into the first years of a researcher's career. Accordingly, these K-30 curriculum, are not leveraged as well as they could be; to do this, there must be new individual K-Awards to support young investigators to gain the needed skills for a successful career in modern clinical and translational research. Thus there is a great need to grow, not cut back, as has been done, K-23 Mentored Patient-Oriented Research Career Development Awards, K-01 Mentored Research Scientist Development Awards, K-08 Mentored Clinical Scientist Development Awards, among other K-Awards based at NIH and AHRQ. Similarly, for T-awards, analogous for selected young physician-investigators who are still in their training phase, also should be increased dramatically. All of these awards mechanism fill critical research training and career development niches, and these mechanisms need bolstered support. Related to this, it would leverage these awards to increase, not decrease as now is the case, K-24 Midcareer Investigator Awards in Patient-Oriented Research for faculty who can act as mentors to the junior faculty.

*We ask the Subcommittee to emphasize its interest in the K-award programs and to urge NIH and AHRQ to continue to increase support for K-awards to develop the needed researchers for transforming biomedical research and improving its impact on health.*

### **3) The importance of continuing to support CER.**

The *American Recovery and Reinvestment Act of 2009* contained \$1.1 billion for CER activities at NIH and the Agency for Healthcare Research and Quality (AHRQ). AHRQ has had a focus on CER especially since the Medicare Modernization Act, and NIH has been supporting critical CER for some time; we are pleased that Congress recognizes the importance of these activities and agree that CER's proper home is in a science agency in which the peer review processes and infrastructure are in place to ensure the highest quality science, rather than creating a new untested entity as a funding agency for this critical work.

Within the \$1.1 billion allocation for CER, \$400 million was provided to NIH. CTSA program recipients should compete well for a portion of these funds as many sites consider CER a crucial component of clinical and translational research. Additionally, the CTSA network is intended to be a collaborative endeavor capable of leveraging great resources to maximize productivity. As CER gains prominence, we hope the

Subcommittee will recognize the CTSA network as an ideal portal for comparative effectiveness research activities. The CTSA network can provide an infrastructure for CER that could immediately put to work the funding allocated to NIH via the stimulus package that would contribute to restoring the originally peer-reviewed and approved budgets.

*We ask the Subcommittee to continue to appreciate and support CER activities at NIH and AHRQ.*

Thank you for this opportunity to present the views and recommendations of the clinical research training community.

#### Appendix: Estimates of costs for fully funding CTSA's based on FY

NATIONAL INSTITUTES OF HEALTH NATIONAL CENTER FOR RESEARCH RESOURCES (NCRR) CTSA/GCRC Estimate Per Current Model (Dollars in Millions)				
Cohort	No.	FY 2009	FY 2010	FY 2011
FY 2006 Grants*	12	\$140	\$140	\$116
FY 2007 Grants*	12	\$120	\$121	\$121
FY 2008 Grants*	14	\$107	\$107	\$107
FY 2009 Grants*	5	\$36	\$36	\$36
FY 2010 Grants*	2		\$14	\$14
FY 2011 Grants*	15			\$100
<b>Total, CTSA Grants</b>	<b>60</b>	<b>\$403</b>	<b>\$418</b>	<b>\$494</b>
CTSA Support Contract		\$3	\$3	\$3
K30 Recompensation			\$5	\$1
<b>Total, CTSA's</b>		<b>\$406</b>	<b>\$426</b>	<b>\$497</b>
<b>GCRC's</b>		<b>\$69</b>	<b>\$41</b>	<b>\$3</b>
<b>Total, CTSA's/GCRC's</b>		<b>\$475</b>	<b>\$467</b>	<b>\$500</b>

CTSA/GCRC Estimate If Requested Amount Awarded (Dollars in Millions)				
Cohort	No.	FY 2009	FY 2010	FY 2011
FY 2006 Grants*	12	\$140	\$140	\$140
FY 2007 Grants*	12	\$158	\$158	\$158
FY 2008 Grants*	14	\$155	\$155	\$155
FY 2009 Grants*	5	\$50	\$50	\$50
FY 2010 Grants*	2		\$21	\$21
FY 2011 Grants*	15			\$142
<b>Total, CTSA Grants</b>	<b>60</b>	<b>\$503</b>	<b>\$524</b>	<b>\$666</b>
CTSA Support Contract		\$3	\$3	\$3
K30 Recompensation			\$5	\$1
<b>Total, CTSA's</b>		<b>\$506</b>	<b>\$532</b>	<b>\$669</b>
<b>GCRC's</b>		<b>\$69</b>	<b>\$41</b>	<b>\$3</b>
<b>Total, CTSA's/GCRC's</b>		<b>\$575</b>	<b>\$573</b>	<b>\$672</b>

- It would cost \$666 million to fund 60 CTSA's at the amounts requested by the institutions, which is \$166 million more than the \$500 million budget.

Difference (Dollars in Millions)				
Cohort	No.	FY 2009	FY 2010	FY 2011
FY 2006 Grants*	12	\$0	\$0	\$24
FY 2007 Grants*	12	\$38	\$37	\$37
FY 2008 Grants*	14	\$48	\$48	\$48
FY 2009 Grants*	5	\$14	\$14	\$14
FY 2010 Grants*	2	\$0	\$7	\$7
FY 2011 Grants*	15	\$0	\$0	\$42
<b>Total, CTSA Grants</b>	<b>60</b>	<b>\$100</b>	<b>\$106</b>	<b>\$172</b>
CTSA Support Contract		\$0	\$0	\$0
K30 Recompensation		\$0	\$0	\$0
<b>Total, CTSA's</b>		<b>\$100</b>	<b>\$106</b>	<b>\$172</b>
<b>GCRC's</b>		<b>\$0</b>	<b>\$0</b>	<b>\$0</b>
<b>Total, CTSA's/GCRC's</b>		<b>\$100</b>	<b>\$106</b>	<b>\$172</b>

- It would cost an additional \$100 million in FY2009, \$106 million in FY 2010, and \$172 million in FY2011 to fund the CTSA's at the amounts requested by the institutions.

\*UL1, KL2, and TL1 awards

**CURRICULUM VITAE**

**Harry Paul Selker, MD, MSPH**

Institute for Clinical Research and Health Policy Studies  
 Tufts Medical Center  
 800 Washington Street, #63  
 Boston, MA 02111  
 Tel: (617) 636-5009  
 E-mail: hselker@tuftsmedicalcenter.org

**CURRENT POSITIONS:**

**Dean**, Tufts Clinical and Translational Science Institute  
 Tufts University  
**Executive Director**, Institute for Clinical Research and Health Policy Studies  
 Chief, Division of Clinical Care Research, Department of Medicine  
 Director, Center for Cardiovascular Health Services Research  
 Tufts Medical Center  
**Professor of Medicine**, Tufts University School of Medicine  
**Professor and Program Director**, Clinical Research Graduate Program  
 Tufts University Sackler School of Graduate Biomedical Sciences

**EDUCATION:**

**Reed College**, Portland, Oregon, BA, 1974  
**Brown University**, Providence, Rhode Island, MD, 1978  
**University of California**, Los Angeles, MSPH, 1984

**TRAINING:**

**UCLA/Cedars-Sinai Medical Center**, Los Angeles, CA  
 Intern in Internal Medicine, 1978-1979  
**Boston City Hospital**  
 Junior Resident in Internal Medicine, 1979-1980  
 Senior Resident in Internal Medicine, 1980-1981  
**Boston University Medical Center/University Hospital**  
 Chief Medical Resident, 1981-1982  
**UCLA School of Medicine**, Los Angeles, CA  
 Department of Medicine  
 Robert Wood Johnson Clinical Scholar, 1982-1984

**PROFESSIONAL SOCIETY MEMBERSHIPS:**

American Association for the Advancement of Science (Life Member), American College of Physicians (Fellow), American Federation for Medical Research (AFMR [formerly AFMR]), American Heart Association (Fellow, Council on Clinical Cardiology), American Public Health Association, Association of American Physicians (AAP), Association for Health Services Research, International Society for Computerized Electrocardiology, International Society of Technology Assessment in Health Care, Massachusetts Medical Society, Society for General Internal Medicine (SGIM), Society for Medical Decision Making

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Harry P. Selker, MD, MSPH  
Dean, Tufts University Clinical and Translational Science Institute  
Executive Director, Tufts Medical Center Institute for Clinical Research and  
Health Policy Studies  
Mail: 800 Washington Street, # 63, Boston, MA 02111  
Administrative Office phone: (617) 636-5009, fax 636-8023

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Association for Clinical Research Training  
National Alliance of Societies for Clinical Research Resources

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

X Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

Please see attached.

Signature:  Date: March 11, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

**ACRT:**

1R13 RR025017-01

\$40,000 03/15/08 – 02/28/09

NIH/NCRR

Clinical Research Training 2008

The purpose of this grant is to sponsor the 2008 Clinical Research Training Conference.

**Dr. Selker:**

Tufts University Clinical and Translational Science Institute

The Clinical and Translational Science Award issued by the NIH (NCRR) designed to spur the transformation of clinical research.

U54 RR025752/KL2 RR025751-01A1

NIH/NCRR

\$20,000,000; 5/19/08-4/30/13

Tufts-NEMC-Sackler Clinical Research Curriculum

K30 RR022266

NCRR

\$1,500,000; 6/1/05-5/31/09

IMMEDIATE (Immediate Myocardial Metabolic Enhancement During Initial Assessment and Treatment in Emergency care) Trial

U01 HL077821

NIH National Heart Lung and Blood Institute (NHLBI)

\$ 35,585,849; 9/01/04-8/31/09

Clinical Care and Health Services Research Fellowship

T32 HS00060

AHRQ

\$2,299,380; 9/30/93 to 6/30/13

EMS-Based TIPI-IS Cardiac Care QI/Error Reduction System

UCI-HSO15124

AHRQ

\$3,000,000: (\$1,500,000; AHRQ Matching \$1,500,000), 9/30/04-9/29/07

General Clinical Research Center at Tufts-New England Medical

2 MO1 RR00054-40A1

NIH/NCRR

\$2,092,660/per year; 3/1/1991-2/28/2006, NCE 2/28/08

WEDNESDAY, MARCH 18, 2009.

## GENETIC ALLIANCE

### WITNESS

#### SHARON F. TERRY

Mr. OBEY. I am going to ask the remaining three witnesses to try to hold their testimony to about three minutes, because, otherwise, the last person on the list is going to have to wait about 45 minutes to be heard because of these votes.

Next, Sharon Terry, Genetic Alliance.

Ms. TERRY. Chairman Obey, Ranking Member, and the Subcommittee, thank you very much for the opportunity to testify before you today on behalf of all Americans who seek therapies and treatments for genetic diseases. I did not choose this work as my career; this vocation was bestowed on me more than 14 years ago when my own children were diagnosed with pseudoxanthoma elasticum. In my capacity as President and CEO of Genetic Alliance, I serve the 10,000 health-related organizations in our network.

I have four requests and one statement, all in the context of the organic linkages we as a society are experiencing in global finance, social networking, and so on.

Number one, we ask that you focus a substantial amount of funding on health information technology that balances privacy with access; two, that HHS develop a strategic, long-term plan that involves innovative translational tools to enhance the clinical adoption of discovery research. We envision two projects under this: the first, a large cohort study enrolling millions of Americans; and, the second, increased and substantial funding for the newly established NIH Rare and Neglected Diseases Initiative.

Through the NIH road map libraries, we have been able to identify disease probes, and it is time to bring them through to drug development.

Three, a mandatory registry for genetic and genomic tests should be developed, and oversight of the clinical laboratory quality systems by the CLIA program should be strengthened.

Four, the Health Resources and Services Administration should receive funding commensurate with its sister agencies so the focus can shift from basic research to treatment and services.

And, finally, we must take our advocacy, research and services and policy to the next level and establish a collaborative approach. Until now, earmarking has been reflective of our collective understanding of this system and how to approach it. We now recognize that earmarking represents fragmentation and segmented communication. It is time to work together to bring us a systemic response.

The collaboration that we seek on the Federal level must also take place in the nonprofit community. Many disease advocacy organizations move forward in an isolated manner to address their specific issues and needs, and historically, though progress has been made, these lessons are not shared with the community at large. This impedes the advances we need. Biology is systems based and, since sequencing the human genome, we know there are

gene families, pathways, and other more effective ways to understand diseases. There are many examples of treatments and cures for diseases coming from an unexpected direction.

Congressional earmarks for specific diseases have contributed to a siloed effect and have stifled progress for the greater good. It is possible they also stymie progress on that very disease. It is time to move away from earmarking as a solution.

Every effort must be made to disseminate success and to learn from failures. We acknowledge that the budget and appropriation process must include prioritization and differentiation. We can go much further together. Let us step into the future as collaborators who build shared infrastructure that accelerate our work beyond anything what anyone can do alone.

We look forward to partnering with you and the Federal agencies to create this network model. Thank you.

[The information follows:]

House Committee on Appropriations Subcommittee on Labor, Health & Human Services,  
Education, and Related Agencies



Written Public Testimony of

Sharon F. Terry, President & CEO, Genetic Alliance, Washington, DC  
sterry@geneticalliance.org, Phone: 202.966.5557 x201  
Representing Genetic Alliance, March 18, 2009, 10:00 AM

#### Summary

##### **Health Information Technology**

We ask that you focus a substantial amount of funding on health information technology to create a research to healthcare services continuum that leverages current technologies.

##### **Strategic, Long-term Translational Research Plan**

HHS, primarily through NIH, but in close collaboration with other agencies, should develop a strategic, long-term plan that includes new approaches and innovative translational tools to enhance the clinical adoption of discovery research.

We envision two projects of this type. The first is a cohort study, using robust health information technology and enrolling millions of Americans in a variety of studies, that enables large numbers of clinical trials. The second project involves increased and substantial funding for the Rare and Neglected Disease Initiative, first funded in this current fiscal year

##### **Regulatory Oversight**

A registry for genetic tests should be developed and maintained that includes the name of the laboratory performing a specific test, the name of the laboratory or manufacturer that developed the test, and information to support claims about the analytical validity and clinical validity of that specific test or test method.

Oversight of clinical laboratory quality systems by the CLIA program should be strengthened to assure that the information provided by advanced diagnostic testing is accurate, reliable and timely.

##### **Services**

The Health Resources and Services Administration (HRSA) should also receive funding commensurate with its sister agencies, as the focus on the continuum shifts from basic research to treatments and services.

##### **The Commons**

Now is the time to work together to create a systemic response, not a partial response, in order to solve our health crises. We are aware that the collaboration we seek on the federal level must also take place in the nonprofit community. Many disease advocacy organizations move forward in an isolated manner to address their specific issues and needs. It is time to move away from earmarking as a solution. Let us step into the future as collaborators who build shared infrastructure and solutions that accelerate our work beyond what anyone can do alone.

We look forward to partnering with Congress and the Federal agencies to create this networked model for improved health for all.



House Committee on Appropriations Subcommittee on Labor, Health & Human Services,  
Education, and Related Agencies



Written Public Testimony  
Sharon F. Terry, President & CEO, Genetic Alliance

For release on delivery, expected:  
March 18, 2009  
10:00 AM

Chairman Obey, Representative Tiahrt, and members of the subcommittee, thank you very much for this opportunity to testify today on behalf of Genetic Alliance, and in fact, on behalf of all Americans who seek therapies and treatments for genetic diseases.

I did not choose this work as my career; this vocation was bestowed on me more than 14 years ago when my two children were diagnosed with a genetic disease called pseudoxanthoma elasticum (PXE). In my capacity as president and CEO of Genetic Alliance, I serve the 10,000 health related organizations in our network, of which 1,000 are dedicated to specific diseases.

Genetic Alliance was founded in 1986 as a support group for support groups, building capacity in those organizations. Today, our mission is to transform health using the tools and technologies born through the study of genetics and genomics. We actively engage all stakeholders to create novel partnerships, improve health systems, and revolutionize access to information to enable translation of research into services.

As a result, we are interested in all appropriations related to health, and we are aware that the commitment of this committee, the 111<sup>th</sup> Congress, in collaboration with the Administration of President Obama, is immense. We are grateful for Chairman Obey's significant contributions to important and meaningful HHS appropriations over the years. We ask that bold leadership continue to drive appropriations to reflect the extraordinary opportunities and challenges of health research and services today.

Our world is interconnected; we continually witness new organic linkages in global finance, social networking, and health and disease. To that end, we have several specific requests, and a final comment.

#### **Health Information Technology**

We ask that you focus a substantial amount of funding on health information technology to create a research to healthcare services continuum that leverages current technologies. All of the

current systems around research and services are built on cottage industry models and need to be brought into the 21<sup>st</sup> century commensurate with and exceeding the standards of other industries, such as the financial services industry. Further, privacy, confidentiality and access can all be achieved with forward thinking solutions.

#### **Strategic, Long-term Translational Research Plan**

HHS, primarily through NIH, but in close collaboration with other agencies, should develop a strategic, long-term plan that includes new approaches and innovative translational tools to enhance the clinical adoption of discovery research. This will require strong leadership to catalyze unprecedented levels of collaboration and coordination. The Human Genome Project is a model for the execution of a large project requiring vision, planning and collaboration. Furthermore, the recent passage of the Genetic Information Nondiscrimination Act, for which we applaud the US Congress, paves the way for needed advances in health through genetics and genomics.

We envision two projects of this type. The first is a cohort study, using robust health information technology and enrolling millions of Americans in a variety of studies, that enables large numbers of clinical trials. A large, national cohort study should be complemented by CDC surveillance for all diseases, along with the resources to initiate and manage essential services.

The second project involves increased and substantial funding for the Rare and Neglected Disease Initiative, first funded in this current fiscal year. There have been dramatic advances in understanding the causes of many rare and neglected diseases in recent years. The Human Genome Project has helped to define the molecular basis of many diseases that were known only by phenotype, or physical characteristics. This brings scientists to the point of being able to engage in target-based drug development. Through programs such as the NIH Roadmap Molecular Libraries initiative, scientists are gaining access to high throughput screening (HTS) of chemical compound libraries, and are successfully identifying research probes for disease-related targets. By the end of 2008, the NIH Molecular Libraries screening network had identified 60 chemical probes with activity against the desired target. Some of these are potentially therapeutic. In one example, a small molecule compound has been identified and been shown to cure schistosomiasis in an animal model. Schistosomiasis affects 250 million people worldwide.

Like the Genome Project, the Rare and Neglected Disease Initiative, in partnership with industry, advocacy, and academia, will develop novel technologies and ultimately new paradigms to develop drugs for diseases that offer little incentive for focused attention.

#### **Regulatory Oversight**

Appropriations must provide adequate funding for the Food and Drug Administration (FDA) and Centers for Medicare & Medicaid Services (CMS) to coordinate oversight and regulation of genetic and genomic testing, as the cornerstone of personalized medicine. FDA lacks the resources to address issues related to genetics and genomics. CMS should further seek new and creative ways, with full stakeholder participation, for coding, coverage and reimbursement of genomic tests that will encourage innovation and not penalize or reduce reimbursement for established clinical laboratory tests.

A registry for genetic tests should be developed and maintained that includes the name of the laboratory performing a specific test, the name of the laboratory or manufacturer that developed the test, and information to support claims about the analytical validity and clinical validity of that specific test or test method. Submission of information to this registry should be mandatory for all advanced diagnostic assays. It is critical that an agency capable of integrating this registry with other databases—such as NIH or FDA—is given the necessary support to do so.

Oversight of clinical laboratory quality systems by the CLIA program should be strengthened to assure that the information provided by advanced diagnostic testing is accurate, reliable and timely. FDA and the Centers for Medicare & Medicaid Services (CMS) should avoid unnecessary duplication in oversight and reconcile any conflicts in regulation between the medical device rules and regulations under CLIA.

In the realm of rare diseases and orphan products, increased funding is needed to create systems that allow the FDA to be a leader in innovative oversight, which enables development of rare disease tests and therapeutics.

#### **Services**

The Health Resources and Services Administration (HRSA) should also receive funding commensurate with its sister agencies, as the focus on the continuum shifts from basic research to treatments and services. This should include a systems-based approach for newborn screening and follow-up, with adequate support for the various state programs. Further, HRSA should lead the nation in preparation for the issues that will arise as prenatal, newborn, and childhood screening—including direct-to-consumer—become widely available. The health literacy and education needs of the nation will increase, and adequate resources should be put toward health professional and consumer education to enable empowered decision-making.

The Social Security Administration is to be applauded for its Compassionate Allowances initiative, a way to expedite the processing of disability claims for applicants whose medical conditions are so severe that they obviously meet Social Security's standards. Resources need to be allocated to allow a more comprehensive rollout beyond the initial 50 conditions.

#### **The Commons**

We must take our advocacy, research, services and policy to the next level and establish a networked approach that discovers treatments and manages disease. Until now, earmarking has been reflective of our collective understanding of the system and how to approach it. Yet when we look specifically at appropriations and funding as the energy to empower health systems, we recognize that earmarking is not an example of interconnectivity. Rather, it represents isolation, fragmentation, and segmented communication. Now is the time to work together to create a systemic response, not a partial response, in order to solve our health crises.

Disease advocacy organizations have worked together for many decades to drive transformation: for example, passage of the Genetic Information Nondiscrimination Act of 2008 and the Newborn Screening Saves Lives Act of 2008, and the lifting of the ban on federal funding for stem cells most recently.

These achievements teach us that working together toward a common goal is key to success. It is becoming increasingly clear that the transformation of basic science to services, which so many of us seek, will require deep and meaningful collaboration. This vision of a commons would necessarily include funds to build adequate infrastructure, provide resources, and create and support networks for all disease-specific interests to systematically address their needs—e.g. to electronically aggregate disease-specific natural history data, share methods for establishing best practices for standards of care, and build shared technology resources. We are seeking this on a federal level and ask that the funding be given to HHS agencies to catalyze this transformation.

We are aware that the collaboration we seek on the federal level must also take place in the nonprofit community. Many disease advocacy organizations move forward in an isolated manner to address their specific issues and needs. Historically, progress has been made in these disease-specific silos, and often the lessons learned are never shared with the community at large. This impedes the development of better health. Biology is systems based. Prior to the genomic age in which we work, perhaps it made sense to study diseases based on an organ, or location within the body. However, since sequencing the human genome, we know that there are gene families, pathways, and other more effective ways to understand disease. There are many examples of treatments and cures for diseases coming from an unexpected direction. We work to inspire the disease advocacy community to reflect the interactive, interconnected nature of science and seize the energy inherent in networks.

Congressional earmarks for specific diseases have contributed to this siloed effect, and have ultimately stifled progress for the greater good and the collective community. It is possible, given the systems structure of science, that they also stymie research on the very disease for which an earmark is sought. It is time to move away from earmarking as a solution.

Genetic Alliance strongly supports policy, systems, funding mechanisms, partnerships and collaborations that benefit all stakeholders. This includes tools, technologies and resources that are developed or designed for a specific cause, as long as those developments are freely available to all who can use, adapt, or benefit from their existence. Every effort must be made to disseminate success and to learn from failures. We acknowledge that the budget and appropriation process at any level must include prioritization and differentiation, but disease-specific earmarking should no longer be part of this process. There is not enough time, funding, or resources to study and develop treatments for each disease individually, yet there are millions of people waiting for our help.

Now is the time to strengthen our collaborations, as there have been significant advances in science, technology, knowledge of diseases, and processes for developing treatments. We must collectively share success and mine our failures in developing systems, practices, and initiatives to study diseases and get treatments to those in need. The NIH open access policy is a good example of the openness that must be supported, and we encourage its expansion to all federally funded research results.

We call for a culture shift in the relationship between advocacy, research, services and policy. We are poised to synergize efforts to benefit all stakeholders.

Our long-term needs will no longer be best addressed by earmarking for one organization or one disease. We can go much further together. Let us step into the future as collaborators who build shared infrastructure and solutions that accelerate our work beyond what anyone can do alone.

We look forward to partnering with Congress and the Federal agencies to create this networked model for improved health for all.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

<p>Your Name, Business Address, and Telephone Number: Sharon F. Terry Genetic Alliance 4301 Connecticut Avenue, NW Suite 404 Washington, DC 20008 <a href="mailto:sterry@geneticalliance.org">sterry@geneticalliance.org</a> 202.966.5557 x202</p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing. Genetic Alliance</p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?  YES</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.  See attached list of grants.</p>

Signature:  Date: March 17, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**BIOGRAPHICAL SKETCH**

BIOGRAPHICAL SKETCH			
NAME Sharon Fontaine Terry		POSITION TITLE President and CEO, Genetic Alliance	
EDUCATION/TRAINING			
INSTITUTION and LOCATION	DEGREE	YEAR(s)	FIELD of STUDY
Assumption College, Worcester, MA	MA	1983	Theology
State University of NY at Stony Brook	BA	1979	Earth & Space Sciences

**Positions and Honors**Honors

2005 – Honorary Doctorate, Iona College

2007 – 1<sup>st</sup> Patient Service Award, University of North Carolina Institute for Pharmacogenomics and Individualized Therapy

Academic Appointments

1986-1988 Campus Minister, Instructor, Assumption College, Worcester, MA

1990-2001 Instructor, Museum of Science, Boston, MA

Positions Held - Professional Organizations

1995-present Founding CEO, PXE International, Inc.

2002-present President & CEO, Genetic Alliance

2002-present Board Member, The Biotechnology Institute

2003-present Founding President, Genetic Alliance BioBank Board of Directors

2004-present Board Member, DNA Direct

2005-2008 Member, Cellular, Tissue, and Gene Therapies Advisory Committee, FDA

2005-present Liaison, National Advisory Council for Human Genome Research

2006-present Board Member, 21<sup>st</sup> Century Medicine Coalition

2007-present Liaison, Advisory Committee to the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborn and Children

2007-present Member, IOM Roundtable on Translating Genomic-Based Research for Health

2007-2008 Google Health Advisory Board

2008-present Board Member, National Coalition of Health Professional Education in Genetics

**Selected peer-reviewed publications and presentations**Publications

1. Terry SF, Boyd C. Researching the Biology of PXE: Partnering in the Process. American Journal of Medical Genetics, Volume 106, Issue 3, 2001. pp. 177-184. PMID: 11778977
2. Terry P, Terry SF. Consumer Perspective on Informed Consent and third-party issues. J Contin Educ Health Prof. 2001 Fall;21(4):256-64. PMID: 11803770
3. Terry SF. Pharmacogenetic challenges. Health Aff (Millwood). 2002 Sep-Oct;21(5):307; discussion 307-8. PMID: 12224905
4. Terry SF, Terry PF. A consumer perspective on forensic DNA banking. J Law Med Ethics. 2006 Summer;34(2):408-14. PMID: 16789963
5. Terry SF, Terry PF, Rauen K, Uitto J, Bercovitch L. Advocacy Organizations as Research Organizations: the PXE International example. Nature Reviews Genetics. 2007 Feb; Vol. 8, No. 2. PMID: 17230202
6. Terry, SF. Genetic testing. Genet Test. 2008 Jun;12(2):175-6. PMID: 18554161

**Sharon F. Terry**

**Federal Grants All granted to Genetic Alliance**

**5 U33MC07945-01-00 (PI: Terry, SF) 6/1/2007 – 5/31/2012**

HRSA/Genetic Services Branch National Consumer Center for Genetic Resources & Services

5 years – \$500,000 per year

This grant will enable development of a central infrastructure, providing information and education for consumers regarding genetics. WikiGenetics, WikiAdvocacy, Resource Repository, Disease InfoSearch, Institute for Advocacy and numerous other programs will be run out of this Center.

**3 U33MC07951-01-01 (PI: Terry, SF) 6/1/2007 – 5/31/2010**

HRSA/Genetic Services Branch

Screening for Heritable Disorders in Children: Efficacy from a Family/Consumer Perspective

3 years – \$250,000 per year

This project will ascertain issues to inform the development of models to educate parents, create systems of informed decision-making and provide data to policymakers to determine what tests should be offered. In addition to promoting family-centered care as an outcome of newborn screening while maximizing benefits and reducing harms, this project will recommend specific models for increasing public literacy to aid the translation of genetic information into healthcare.

**3 U33MC07952-01-01 (PI: Terry, SF) 6/1/2007 – 5/31/2010**

HRSA/Genetic Services Branch

Screening for Heritable Disorders in Children: Efficacy from a Family/Consumer Perspective

3 years – \$350,000 per year

This project will use a mixed method and iterative strategy of unstructured interviews, focus groups and structured interviews to understand the experience of families and professionals with respect to false+ screens and carrier identification in newborn screening. The results of the analysis will be used to inform development of models to improve NBS in the emerging context of the medical home.

**3 U33MC00214-05-01 (PI: Terry, SF) 6/1/2006 – 5/31/2009**

HRSA/Genetic Services Branch Community Centered Family Health History

3 years – \$600,000 per year

This project will coordinate the efforts of over 22 communities and create a customizable guide to gathering family health history. The result will be a downloadable, and printable, guide with culturally sensitive components such as stories, pictures, and methods.

**5 U10CCU525036-02 (PI: Terry, SF) 10/1/05 – 9/30/10**

Centers for Disease Control and Prevention Access to Credible Genetics Resources Network

5 years – \$850,000 per year

This project will define evidence-based information, best clinical practices and core competencies, using two conditions as the focus: Duchene Becker Muscular Dystrophy and Fragile X Syndrome. Infrastructure and processes will be established that can be used for other single gene disorders. Materials for patients and providers will be produced and national disseminated broadly in multiple forms.

**5 U33MC00214-04-05 (PI: Terry, SF)**

6/1/02 – 5/30/07 [completed] HRSA/Genetic Services Branch

5 years – \$400,000 per year Genetic Services and Resources Center

This project will connect all of the major HHS information and resource grants, build a central repository, convene an accessible forum, create a family history coalition, with focus on underserved and underrepresented communities.



WEDNESDAY, MARCH 18, 2009.

**MEDICAL LIBRARY ASSOCIATION**

**WITNESS**

**HOPE BARTON**

Mr. OBEY. Next, Medical Library Association, Hope Barton.

Ms. BARTON. Thank you very much for the opportunity to be here today. I am going to go in fast forward mode and maybe speak in some phrases and bullet points.

My name is Hope Barton. I am a medical librarian from the University of Iowa, and I would like to thank the Subcommittee very much for the opportunity to speak today. I am here on behalf of the Medical Library Association and the Association of Academic Health Sciences Libraries, and we work very hard to support the critical role of the National Library of Medicine within the NIH.

We are very pleased that in the 2009 funding package NLM received an \$8,000,000 increase. This is the first meaningful increase we have received in a number of years, and we hope this is a very positive indication of momentum going forward and that there will be increased adequate increases as well every year.

For 2010, we feel that a 7 percent increase would be adequate to keep momentum going, as we have gained a little bit of financing here, and we feel it is important for the databases and the programs that NLM serves.

Our mandates have grown over the years and, as an example of this, the last session of Congress passed FDA amendment legislation that required NLM to play an increased role in the clinicaltrials.gov database. Unfortunately, no monies came with that mandate, so the NLM budget was stretched even further.

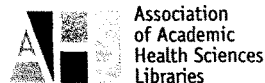
NLM also plays a very important role in disaster preparedness and management, and got very important health information, environmental information to the Katrina area shortly after that hurricane.

Very importantly, we would like to thank the Subcommittee for its leadership in the NIH public access policy. We feel this policy is very important for expediting medical research and also for getting health information out to the citizens of the Country. After all, it is taxpayers' dollars that helped to support the research and the new information that has generated, and we certainly hope that this Subcommittee will continue to support and defend this policy.

Thank you again for the opportunity to speak today.

Mr. OBEY. Thank you. Appreciate it. Thanks for your cooperation on time.

[The information follows:]



**STATEMENT OF  
HOPE BARTON  
DIRECTOR, CENTRAL TECHNICAL SERVICES  
UNIVERSITY OF IOWA LIBRARIES  
IOWA CITY, IA**

**ON BEHALF OF THE  
MEDICAL LIBRARY ASSOCIATION  
AND THE  
ASSOCIATION FOR ACADEMIC HEALTH SCIENCES LIBRARIES  
507 CAPITOL COURT, NE, SUITE 200  
WASHINGTON, DC 20002  
(202) 544-7499**

**REGARDING FISCAL YEAR 2010 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTES OF HEALTH'S  
NATIONAL LIBRARY OF MEDICINE**

**SUBMITTED TO THE  
HOUSE COMMITTEE ON APPROPRIATION'S SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED  
AGENCIES**

**WEDNESDAY, MARCH 18, 2009, 10:00AM**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2010:**

- 1) CONTINUE THE COMMITMENT TO PROVIDING THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL LIBRARY OF MEDICINE (NLM) WITH MEANINGFUL FUNDING INCREASES ON AN ANNUAL BASIS.**
- 2) CONTINUE TO SUPPORT AND DEFEND THE NIH'S PUBLIC ACCESS POLICY, WHICH REQUIRES THAT ALL FINAL, PEER-REVIEWED MANUSCRIPTS ARE MADE AVAILABLE THROUGH NLM'S PUBMED CENTRAL DATABASE WITHIN 12 MONTHS OF PUBLICATION.**
- 3) CONTINUE TO SUPPORT THE MEDICAL LIBRARY COMMUNITY'S IMPORTANT ROLE IN NLM'S OUTREACH, TELEMEDICINE, DISASTER PREPAREDNESS AND HEALTH INFORMATION TECHNOLOGY (HEALTH IT) INITIATIVES.**

On behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL), thank you for the opportunity to present testimony regarding FY 2010 appropriations for the National Library of Medicine (NLM).

MLA is a nonprofit, educational organization with more than 4,000 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

AAHSL is comprised of the directors of the libraries of 142 accredited American and Canadian medical schools belonging to the Association of American Medical Colleges (AAMC). AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health professionals is trained in information-seeking skills that enhance the quality of healthcare delivery.

Together, MLA and AAHSL address health information issues and legislative matters of importance through a joint legislative task force and a Government Relations Committee.

#### **1) THE IMPORTANCE OF ANNUAL FUNDING INCREASES FOR NLM.**

I thank the Committee for its leadership and hard work on the *American Recovery and Reinvestment Act of 2009* (P.L. 111-5), the economic stimulus package. As you know, the important mission of NIH and the important role that NLM plays in fulfilling that mission were hampered by past-years of near level funding. The investment in NIH and NLM provided by the stimulus package will not only create meaningful employment opportunities, it will also revitalize NLM's programs, which are focused on improving the public health.

We are pleased that the recently-passed FY 2009 Omnibus Appropriations package contains funding increases for NIH and NLM that will bolster their baseline budgets. We hope that this funding is an indication of the Subcommittee's intention to provide annual, meaningful increases for NIH and NLM in the coming years.

I am confident that the recovery funding and the FY 2009 budget increases will stimulate the economy, stimulate biomedical research, and in the case of NLM, improve the dissemination of health information to researchers, practitioners, and the general public. Moving forward, it will be critical to provide NIH's baseline budget with the funding increases necessary to allow the short-term growth generated by the stimulus to become a long-term investment towards improved public health through bolstered health information programs.

#### **BUILDING AND FACILITY NEEDS**

NLM has had tremendous growth in its basic functions related to the acquisition, organization and preservation of an ever-expanding collection of biomedical literature. It also has been assigned a growing set of responsibilities related to the collection, management, and dissemination genomic information, clinical trials information, and disaster preparedness and response. As a result, NLM faces a serious shortage of space,

for staff, library materials, and information systems. Digital archiving—once thought to be a solution to the problem of housing physical collections—has only added to the challenge, as materials must often be stored in multiple formats (physical and digital) and as new digital resources demand increasing amounts of storage space. As a result, the space needed for computing facilities has also grown. In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. Further, Senate Report 108-345 that accompanied the FY 2005 appropriations bill acknowledged that the design for the new research facility at NLM had been completed, and the Committee urged NIH to assign a high priority to this construction project so that the information-handling capabilities and biomedical research are not jeopardized.

#### THE GROWING DEMAND FOR NLM'S BASIC SERVICES

As the world's foremost digital library and knowledge repository in the health sciences, NLM provides the critical infrastructure in the form of data repositories and integrated services such as GenBank and PubMed that are helping to revolutionize medicine and advance science to the next important era—individualized medicine based on an individual's unique genetic differences.

NLM's clinical trials database, ClinicalTrials.gov, which was launched in February of 2000 and lists registration information on more than 70,000 U.S. and international trials for a wide range of diseases, also now serves as a repository for summary results information. The expanded system serves not only as a free but invaluable resource for patients and families who are interested in participating in trials of new treatments for a wide range of diseases and conditions, but also as an important source of information for clinicians interested in understanding new treatments and for those involved in evidence-based medicine and comparative effectiveness research.

As the world's largest and most comprehensive medical library, services based on NLM's traditional and electronic collections continue to steadily increase each year. These collections stand at more than 11.4 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare. Without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients have all come to expect.

#### **2) DEFEND PUBLIC ACCESS**

The Appropriations Committee has shown unprecedented foresight and leadership by using the annual spending bills as the vehicle to establish a public access policy at the NIH. The current policy requires that all NIH-funded researchers deposit their final, peer-reviewed manuscripts in NLM's PubMed Central database within 12 months of publication. This policy will not only help NIH better manage its portfolio of research, but will contribute to the development of a biomedical informatics infrastructure that will stimulate further discovery by enabling a much greater and tighter interlinking of

information from NLM's wide-ranging set of databases. It also contributes to outreach initiatives by providing much-needed access to health literature to those without direct access to medical libraries. While the FY 2009 omnibus package made this policy permanent moving forward, challenges remain and we urge the Subcommittee to continue to defend this policy.

### **3) SUPPORT AND ENCOURAGE NLM PARTNERSHIPS WITH THE MEDICAL LIBRARY COMMUNITY.**

#### Outreach and Education

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general public about NLM's services. NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. One example of NLM's leadership is the "Partners in Information Access" program, which is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well positioned to ensure that every public health worker has electronic health information services that can protect the public's health.

With help from Congress, NLM, NIH and the Friends of NLM, launched *NIH MedlinePlus* Magazine in September 2006. This quarterly publication is distributed in doctors' waiting rooms, and provides the public with access to high quality, easily understood health information. Collaborating with the National Alliance for Hispanic Health, a Spanish version is now available, *NIH MedlinePlus Salud*. NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus "information prescriptions" to their patients. This initiative also encourages genetics counselors to prescribe the use of NLM's Genetic Home Reference website.

"Go Local" is another exciting service that engages health sciences libraries and other local and state agencies in the creation of Web sites that link from MedlinePlus to relevant information on local pharmacies, hospitals, doctors, nursing homes, and other health and social services. In Iowa, for example, University of Iowa librarians developed an Iowa Go Local site that enables users to find local health resources by Iowa county or city. It allows Iowa citizens to link directly from a MedlinePlus health topic, for example asthma, to local services, such as clinics, pulmonary specialists, and support groups in the geographic area selected. By collecting such information in one place, Go Local also provides a platform for enhancing access to the information needed to prepare for and respond to disasters and emergencies.

MLA and AAHSL applaud the success of NLM's outreach initiatives, particularly those initiatives that reach out to medical libraries and health consumers. We ask the Committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in FY 2010.

#### EMERGENCY PREPAREDNESS AND RESPONSE

MLA and AAHSL are pleased that NLM has established a Disaster Information Management Research Center to expand NLM's capacity to support disaster response and management initiatives, as recommended in the *NLM Board of Regents Long Range Plan for 2006-2016*. We ask the Subcommittee to show its support for this initiative, which has a major objective of ensuring continuous access to health information and effective use of libraries and librarians when disasters occur. Following Hurricane Katrina, for example, NLM worked with health sciences libraries across the country to provide health professionals and the public with access to needed health and environmental information by: 1) quickly compiling web pages on toxic chemicals and environmental concerns, 2) rapidly providing funds, computers and communication services to assist librarians in the field who were restoring health information services to displaced clinicians and patients and 3) rerouting interlibrary loan requests from the afflicted regions through the NNLM. Presently, libraries are a significant, but underutilized resource for community disaster planning and management efforts, which NLM can help to deploy. With assistance from its National Network of Libraries of Medicine, NLM is working with health sciences libraries to develop continuity of operations and backup plans and is exploring the role that specially trained librarians—disaster information specialists—can play in providing information services to emergency personnel during a crisis. MLA and AAHSL see a clear role for NLM and the National Network of Libraries of Medicine in the nation's disaster preparedness and response activities.

#### HEALTH IT AND BIOINFORMATICS

NLM has played a pivotal role in creating and nurturing the field of biomedical informatics. Not only has NLM developed key biomedical databases, but for nearly 35 years, NLM has supported informatics research and training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country. Many of the country's exemplary electronic health record systems benefited from NLM grant support.

A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free US-wide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records.

MLA and AAHSL encourage the Subcommittee to continue its strong support of NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also support health information technology initiatives in ONCHIT and the Agency for Healthcare Research and Quality that build upon initiatives housed at NLM.

Thank you for the opportunity to present the views of the medical library community.

**Hope Barton**  
**Brief Biography/Curriculum Vitae**

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30+ years experience working in academic health sciences libraries selecting and cataloging library books, journals, and electronic resources; providing library instruction to students, faculty, and staff; providing information services and consultations to students, faculty, staff, and the general public; contributing to the medical information profession through service to the Medical Library Association and other professional organizations via publications, presentations, and community outreach efforts; and contributing to national evidence-based clinical nursing initiatives through instruction and consultations at local, regional, and national workshops.

**Current position (2005-):**

Director of Technical Services, Access Services, and Media Services  
University of Iowa Libraries

**Previous positions:**

Assistant Director, Information Resources (1999-2005)  
Hardin Library for the Health Sciences  
University of Iowa

Coordinator, Materials Processing (1986-1999)  
Hardin Library for the Health Sciences  
University of Iowa

Cataloging Librarian (1974-1984)  
Temple University Dental-Allied Health-Pharmacy Library

**Current professional appointments:**

Chair, Medical Library Association Governmental Relations Committee (2007-2010)  
Chair, Association of Academic Health Sciences Libraries/Medical Library Association  
Joint Legislative Task Force (2008-2010)

**Education**

Muhlenberg College, Allentown, PA B.A. English (cum Laude)  
Rutgers University, New Brunswick, NJ M.S.L.S. Library and Information Science

**Honor Societies**

Beta Phi Mu, national library and information studies honor society

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

<p>Your Name, Business Address, and Telephone Number:</p> <p>Hope Barton          Director, Central Technical Services, Access Services, and Distance Education          Main Library          University of Iowa          Iowa City, IA 52242          1(319) 335-5867</p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p>Medical Library Association          Association of Academic Health Sciences Libraries (AAHSL)</p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?</p> <p>Yes</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p> <p>The Medical Library Association received a \$250,000 grant from the National Library of Medicine, #HHSN276200663511//NO1-LM-6-3511, for a Health Information Literacy Project, September 30, 2006 through September 29, 2008.</p> <p>AAHSL receives \$55,000 annually from the National Library of Medicine for its Leadership Fellows Program.</p>

Signature: Hope D. Barton Date: 3/12/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.



WEDNESDAY, MARCH 18, 2009.

**FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL, AND  
COGNITIVE SCIENCES**

**WITNESS**

**JAMES McCLELLAND**

Mr. OBEY. And, last, Dr. James McClelland, Federation of Behavioral, Psychological, and Cognitive Sciences.

Mr. McCLELLAND. Thanks very much. Today, I will argue that it is essential for Congress to increase support for mind research at NIH because it will have a real impact on human health and human potential.

Mr. OBEY. Especially on the Congress itself.

[Laughter.]

Mr. McCLELLAND. You know, scientific questions can be examined at many levels, and, in the case of the human sciences, these levels range from genes and molecules to organ systems, including the brain, to behavior, to social and cultural context. At the nexus of all these levels is the mind, our thoughts, perceptions, and emotions, the things we identify as ourselves. Mental process is influence and our influence by processes occurring at all other levels. This is why the sciences of mind, brain, and behavior are so relevant to human well-being and human productivity.

It may seem natural to think of heart disease, physical injury, and illnesses ranging from cancer to the common cold as physical conditions disconnected from the mind and brain. But, in fact, research shows that people who have social relationships with many others are healthier and live longer than those with fewer relationships.

What are the mechanisms, the biological and mental processes that lead from social support to better health and longer life? One study focused on married couples. Both members of the couple were admitted to the hospital and received a small skin wound. This occurred on two occasions. On one occasion, they had a discussion about how they support each other; on the other occasion they were induced to have a bit of an argument about a subject they usually disagree on. After the supportive discussion, their wounds actually healed faster.

The work provides a striking demonstration of links across levels of analysis. There is a sound basis for thinking that social support works through the mind to affect more critical illnesses as well, including cancer and heart disease. Building on this base, NIH funding can now support research on the mental processes triggered by social support and on the effects of these processes on the biological response to illness and injury.

If I have one more minute, I just want to make the point that research on the mind can have a huge impact on our children's success in school; not just figuring out how better to teach math or science, but figuring out how to help children think about their own abilities. A common theory is that it helps people to tell them that they are inherently capable, they have an innate intelligence. But recent research suggests that this is actually counter-productive. If you tell people that their brains are flexible, that

they can make them grow, they are like a muscle and they can be strengthened with practice, it actually has a much better effect on their responses to challenge and their attitudes towards school and their ultimate educational achievements.

This is new research, it is evidence-based, goes against intuition, and it is a very important demonstration that research at the level of the mind can really have an impact on outcomes.

In my written testimony, I note many other issues that research on mind, brain, and behavior can address. These further points support the conclusion that sustained funding for research at NIH, including research on mind, brain, and behavior, will lead to significant discoveries and improved health for the American people.

We urge the Subcommittee to support this important work. We recommend an increase for NIH of 7 percent over the fiscal year 2009 appropriations. We also urge comparable support for research on mind, brain, and behavior in other agencies under the Subcommittee's jurisdiction.

Thank you very much.

[The information follows:]



**Testimony of**

**James L. McClelland, Ph.D.  
President-Elect  
Federation of Behavioral, Psychological, and Cognitive Sciences**

**Professor, Department of Psychology  
Director, Center for Mind, Brain, and Computation  
Stanford University  
Stanford, CA**

**to the**

**United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies**

**March 18, 2009, 10:00 am**

**United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**

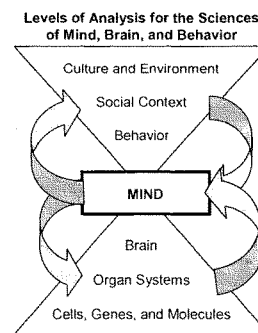
*Testimony of James L. McClelland, Ph.D.  
President-Elect, Federation of Behavioral, Psychological, and Cognitive Sciences  
Professor, Department of Psychology  
Director, Center for Mind, Brain, and Computation  
Stanford University  
March 18, 2009, 10:00 am*

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to testify in support of research in the sciences of mind, brain, and behavior at the National Institutes of Health. My name is James L. (Jay) McClelland. I am President-Elect of the Federation of Behavioral, Psychological, and Cognitive Sciences, an umbrella organization representing twenty-one (21) scientific societies, as well as thirty-nine (39) academic affiliates and two (2) corporate affiliates. As a cognitive neuroscience researcher at Stanford, I am aware of the important research involving mind, brain, and behavior that is funded by NIH. In fact, I have served on peer-review committees and Advisory Councils for the agency, and I have received support from NIH for my own research.

At the Federation, we are pleased that science – including the study of mind, brain, and behavior – is becoming a national priority, and we thank this Subcommittee for its prior support. This directed attention will result in breakthroughs that will have far-reaching impact on human well-being and human potential, affecting areas such as health, education, and the workplace, and in turn, our nation's long-term economic growth. Basic and applied research that examines how the mind functions, its relation to behavior and society, and its underlying biology are critically important in our quest to achieve our nation's goals.

In the scientific community, we often speak of “levels of analysis.” By this, we mean that issues can be examined at various levels – ranging from genes and molecules, to organ systems including the brain, to behavior and social relationships, and even to the level of culture and environment. At the nexus of all of these levels is the level of the Mind – of our thoughts, perceptions, and emotions, the things we identify as ourselves. These mental processes influence and are influenced by all other levels of analysis. Scientists work at different levels, some focusing on important advances that can be gained at one level (e.g., cells), while others may examine complex relationships across levels. **All** these levels and their interrelationships are important if we are truly to understand the human condition and thereby enhance human health, potential, and productivity.



To underscore this point, I would like to highlight one example from the area of health and another from the area of education which may also benefit from basic research on the mind funded by NIH.

*The role of social context and social support in health*

Heart disease, physical injury, and other maladies ranging from cancer to the common cold are all physical conditions. With these kinds of conditions, it is tempting to think that the body exists on a plane disconnected from the mind and brain, and therefore that the effort to understand and treat such illnesses should focus only on their physical basis. But in fact, research shows that social support and social context play important roles in all of these conditions.

People who have relationships with many others – partners, friends, co-workers, or relatives – are healthier overall and live longer than their counterparts who have fewer relationships. Furthermore, it is often found that people whose relationships with others are supportive and harmonious are often healthier and live longer than those whose relationships are marked by conflict and discord.

These studies show positive relationships between social support and health, an important first step. But we need to know more. What are the mechanisms – the mental and biological processes – that lead from social support to better health and longer life? More recent research begins to take up answers to these questions.

One line of work examines how individuals with different amounts of social support respond to an experimentally administered virus – one that can produce the standard symptoms of a common cold. Individuals with high levels of social support and individuals with lower levels of social support both received the same dose of the virus, but those with less social support got sicker. They didn't just feel sicker – their levels of virus were higher, and their physical symptoms lasted longer.

Another study goes even further in demonstrating the differing health consequences of social harmony and discord. In this experiment, married couples were admitted to a hospital on two separate occasions. On one occasion, the couples were encouraged to talk about how they could best support each other. On the other occasion, the couples were asked to talk about an issue they often argued about. On both occasions, members of the couple received experimental skin wounds. After the discussion of mutual support, the wounds healed faster than they did after the discussion of an area of conflict. Based on this research, it now seems clear that the content of social interactions can have real health consequences.

Small skin wounds, perhaps, are not the first priority of health research. But these provide important experimental models in which scientists can begin to explore the underlying mechanisms. A key finding of the couples study was the observation that immune responses were initially stronger after the more supportive interaction. There is a sound basis for thinking that social support affects more critical illnesses as well, such as cancer and heart disease.

Future effort can now be directed toward understanding how social support “gets under the skin” and affects the way the body responds to injuries and illnesses.

*The role of beliefs in school performance and educational achievement*

It is important to understand that the sciences of the mind can enhance our efforts to promote human potential as well as human health. Given the new administration’s emphasis on education, and the fact that education falls within the purview of this subcommittee, I would like to describe research on how the way we think affects success in school.

There are different theories about this issue. One prominent theory holds that what is most important is to make children (and adults, too) feel good about themselves. If only we all thought we were inherently capable, the theory goes, we would be able to fulfill our full potential. This theory is believable, and it has been influential, but it actually runs contrary to recent research. These studies show that telling kids they are smart can actually reduce their achievement levels and even their IQ test scores.

This line of research is based on the idea that the thoughts and beliefs we have about the basis of our abilities can influence our educational accomplishments and outcomes. These studies show that people who think their abilities are fixed do less well in school and respond less well to challenges than people who think that they can shape their abilities through effort. Luckily, these studies also show that it is possible to shift people from one theory to another, depending on what they are told. When students are praised for their intelligence, it moves them towards a fixed theory. This saps their energy, and makes them respond poorly to challenges. When students are praised instead for their effort, they move toward a flexible, malleable conception of themselves. With this kind of self-concept in place, they are energized to engage their best efforts, and they are better equipped to respond to challenges.

The consequences of these interventions are real, and they are lasting. In one study, students entering a rigorous university viewed a film discussing how the brain can make new connections throughout life and how it grows when in response to effort and engagement. They also wrote a letter to a younger student on the malleability of the brain and the role of effort. At the end of their first semester, these students valued their academic experience more and achieved higher grade-point averages than students who did not receive this intervention. Similar findings arose in a study of children’s transition to junior high school. Students were taught good study skills, and they were also taught that the brain is like a muscle that can grow if you exercise it. These children showed improvements in their effort and in their grades. Which was more important, you ask: Training in study skills, or learning that effort can lead you to strengthen your brain? A group receiving the same study skill training but were not taught that the brain can grow if exercised provided the crucial evidence: This group showed no increase in effort and no increase in their grades. The results indicate that learning that effort can strengthen your mental capacities can have a big impact on academic performance.

This work, based on the role of beliefs, has so far been applied primarily in an educational setting. The potential applications to socialization, health behaviors, and a wide range of other

issues all deserve thorough investigation – the potential impact on health and well-being is enormous.

***Evidence-based research on social support, beliefs, and outcomes***

The two kinds of work I have just described represent the kinds of insights that scientific research on mind, brain and behavior has to offer. I want to stress that the research I have described involves controlled, experimental studies of just the same kind that are required to demonstrate causal effectiveness of medications or other interventions. Based on these investigations, we know that social support can influence health outcomes, and we know that how you think about your abilities affects your educational attitudes and outcomes. We have, however, a long way to go to understand both of these findings. Exactly how does social support work its way through the mechanisms of the mind to mobilize the body's defenses to fight injury and illness? Exactly what is it that changes in the mind when a student stops thinking of his abilities as fixed attributes? What other kinds of aspects of people's health, well-being, and social behavior can be affected by these kinds of interventions? It will only be through sustained, on-going support for research that progress will be made in answering these questions.

***Broad impact of research on mind, brain, and behavior***

With investments, cutting edge research on the sciences of mind, brain, and behavior can tell us many things:

- how individuals make decisions to engage in healthy behaviors and how to communicate more clearly the health risk associated with certain behaviors;
- what processes are involved in learning, including how the brain and mind interact in cognitive processes that bear on health issues;
- how behavior interacts with genes and hormones to influence unhealthy behaviors including excessive eating and drinking, risk-seeking behaviors, and aggression;
- what cognitive or affective processes are involved in neurological and psychiatric disorders;
- how cognition and emotion develop throughout the lifespan from birth to the elder years, and the effects of interventions at different stages of development;
- the interaction of cognitive, social, and biological processes in the prevention and treatment of addiction;
- how personal (individual traits, attitudes, and goals) and social factors (incentives or community social norms) influence health outcomes, decisions about health behaviors, and health care;
- how the structure and nature of people's social networks can predict ordinary health habits as well as human responses during health epidemics, natural or human-caused disasters, or other crises, and how to intervene effectively;
- how our knowledge of the interactions of the mind and body can be applied in clinical, educational, and work settings;
- how human limitations and capacities must be understood and taken into account when designing machines, devices, and systems, including new health information technologies; and,

- how disparities in health outcomes can be understood, remediated, and prevented.

NIH is a world leader in sponsoring basic and applied research that will help us understand, prevent, and treat disease. Concentrated and sustained research in the sciences of mind, brain, and behavior through NIH will lead to significant discoveries and improved health for the American people. Keeping America healthy will benefit our country in numerous ways. We encourage this Subcommittee to support this important work and recommend an increase for NIH of at least seven (7) percent over the FY 2009 appropriations. We also urge comparable support for this important research in other agencies under this Subcommittee's jurisdiction. Once again, thank you for the opportunity to provide this testimony to the Subcommittee.



### Federation of Behavioral, Psychological, and Cognitive Sciences

#### Member Societies

American Educational Research Association	Society for Behavioral Neuroendocrinology
American Psychological Association	Society for Computers in Psychology
Association for Applied Psychophysiology and Biofeedback	Society of Experimental Social Psychology
Association for Behavior Analysis International	Society for Industrial and Organizational Psychology
Behavior Genetics Association	Society for Judgment and Decision Making
Cognitive Science Society	Society for Mathematical Psychology
Human Factors and Ergonomics Society	Society of Multivariate Experimental Psychology
International Society for Developmental Psychobiology	Society for Personality and Social Psychology
Massachusetts Neuropsychological Society	Society for Psychophysiological Research
National Academy of Neuropsychology	Society for Research in Psychopathology
Psychonomic Society	

#### University Affiliates

Boston University	University of California, Davis
Bowling Green State University	University of California, San Diego
Dartmouth College	University of Cincinnati
Duke University	University of Colorado at Boulder
Emory University	University of Delaware
Emporia State University	University of Denver
Georgia Institute of Technology	University of Illinois, Urbana-Champaign
Kent State University	University of Kansas
Michigan State University	University of Maryland, College Park
Ohio State University	University of Miami
Pennsylvania State University	University of Michigan
Princeton University	University of North Carolina, Greensboro
Purdue University	University of North Texas
Rice University	University of Pittsburgh
Stanford University	University of Southern California
Temple University	Virginia Tech
University of Arizona	Yale University

#### American Psychological Association Division Affiliates

Division 1: Society for General Psychology  
 Division 3: Experimental Psychology  
 Division 6: Behavioral Neuroscience and Comparative Psychology  
 Division 7: Developmental Psychology  
 Division 8: Society for Personality and Social Psychology  
 Division 14: Society for Industrial and Organizational Psychology  
 Division 21: Applied Experimental and Engineering Psychology  
 Division 25: Behavior Analysis  
 Division 28: Psychopharmacology and Substance Abuse  
 Division 50: Addictions

#### Corporate Affiliates

Sage Publications, Inc.  
 Worth Publishers

**James L. McClelland**  
**One Page Biography**

James L. (Jay) McClelland received his Ph.D. in Cognitive Psychology from the University of Pennsylvania in 1975. He served on the faculty of the University of California, San Diego, before moving to Carnegie Mellon in 1984, where he became a University Professor and held the Walter Van Dyke Bingham Chair in Psychology and Cognitive Neuroscience. He was a founding Co-Director of the Center for the Neural Basis of Cognition, a joint project of Carnegie Mellon and the University of Pittsburgh. He served as Co-Director until 2006. In that year he moved to Stanford University, where he is now Professor of Psychology and founding Director of the Center for Mind, Brain and Computation. McClelland currently teaches cognitive psychology and cognitive neuroscience and conducts research on learning, memory, conceptual development, spoken language, decision making, and semantic cognition.

Over his career, McClelland has contributed to both the experimental and theoretical literatures in a number of areas, most notably in the development and application of a computational framework for understanding brain function, called the *parallel distributed processing* framework. McClelland was a co-founder with David E. Rumelhart of the Parallel Distributed Processing research group, and he and Rumelhart led the effort leading to the publication in 1986 of the two-volume book, *Parallel Distributed Processing*, in which the framework was laid out and applied to a wide range of topics in cognitive psychology and cognitive neuroscience. Since that time, McClelland has applied models developed in this framework to address topics ranging from the dynamics of the decision process in split-second decision making situations and changes in the content and structure of conceptual knowledge over the course of child development. Other topics include aspects of first and second language learning, the neurobiology of memory, and the loss of conceptual knowledge in dementia.

McClelland and Rumelhart jointly received the 1993 Howard Crosby Warren Medal from the Society of Experimental Psychologists, the 1996 Distinguished Scientific Contribution Award from the American Psychological Association, the 2001 Grawemeyer Prize in Psychology, and the 2002 IEEE Neural Networks Pioneer Award for their joint work. McClelland has served as Senior Editor of *Cognitive Science*, as President of the Cognitive Science Society, as chair of an NIH Peer-Review Panel on Integrative, Functional and Cognitive Neuroscience, and as a member of the National Advisory Mental Health Council. He is currently president-elect of the Federation of the Behavioral, Psychological, and Cognitive Sciences. He is a member of the National Academy of Sciences, and he has received the William James Fellow Award from the Association for Psychological Science for lifetime contributions to the basic science of psychology. In fall, 2009, he will become Chair of the Stanford Psychology Department.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

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<p>Your Name, Business Address, and Telephone Number: James L. McClelland, Ph.D. Department of Psychology 344 Jordan Hall, 450 Serra Mall Stanford University Stanford, CA 94305</p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p>NGO: Federation of Behavioral, Psychological, and Cognitive Sciences</p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?</p> <p style="text-align: center;">Yes</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p> <p>None to the Federation of Behavioral, Psychological and Cognitive Sciences.</p> <p>Grants or Contracts to McClelland:</p> <ul style="list-style-type: none"><li>• Air Force Office of Scientific Research. MURI Program. July 1, 2007 – July 1, 2012, \$7,290,000.00</li><li>• NSF IGERT Training Grant. July 1, 2008 – June 30, 2013, \$3,200,000.00</li></ul>

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you very much. We have five minutes to make that vote, so we stand adjourned.

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AFTERNOON SESSION

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WEDNESDAY, MARCH 18, 2009.

TESTIMONY OF INTERESTED INDIVIDUALS AND  
ORGANIZATIONS

Mr. OBEY. Well, good afternoon, everybody. Let me thank all of you for coming.

Let me thank the witnesses who will appear before us here today, and let me explain a couple of matters of procedure. I am going to have to insist that people limit their testimony to four minutes. If we don't, there are people who are never going to get heard because we have other things to do after this hearing is over today, and we can't ignore those responsibilities either.

We also have a practical problem. There will be a number of votes that occur on the House Floor sometime around 3:00, and that will eat substantially into the time of the witnesses available. So I am going to ask all of the witnesses to hold their testimony to four minutes sharp. When that red light goes on, I am going to have to ask you to conclude your statement.

As I said this morning, we have finished action on the recovery package, and we finished action on the Omnibus Appropriation Bill. Now we want to turn to the new budget for fiscal year 2010. The problem we have is that every time we have a new President, it takes a while for the Executive Branch to send down their budget request, and we do not yet have a budget request from the White House.

I don't say that by way of criticism. It is normal, given the turnover of administrations, but it does create an inconvenience for this Committee and makes it much more difficult for us to do our work on the schedule we set.

So we are trying to get as much work under our belts as possible, including public witnesses, and a number of other hearings, so that when we do get the budget we can move swiftly to analyze it, mark it up, and move on with the process.

At this point, let me call on our new Ranking Member, Mr. TIAHRT, for any comments he has before we listen to the witnesses today.

Mr. TIAHRT. Thank you, Mr. Chairman. Thank you for keeping us on track. We have covered a lot of territory today, and we appreciate the cooperation from the witnesses, and we are anxious to hear your testimony.

Thank you, Mr. Chairman.

Mr. OBEY. One other thing, as I said, this morning. Please understand if you don't get questions from the panel, which is normal during this testimony, as it is not because of a lack of interest. We are simply trying to save as much time as possible for the witnesses.

We have all heard each other's dulcet tones often. We will try to limit our enthusiasm, or, as Archie Bunker said to Edith once, we will try to stifle ourselves. [Laughter.]

With that, let me ask Ms. Roybal-Allard to begin the process.

Ms. ROYBAL-ALLARD. First, Mr. Chairman, let me thank you for having these very important public testimony hearings.

And I just want to apologize in advance to the witnesses for having to leave early because I also have another hearing going on at the same time as this one, so I will to leave.

Mr. Chairman, I have the privilege of introducing Mikayla Minnig, who will be testifying about the importance of funding arthritis research. Mikayla is a fifth grader who lives in the City of Downey in my Congressional district. Like many active 10-year-olds, Mikayla divides her time between school, Girl Scouts and cheerleading. But what makes Mikayla remarkable is that she has done all of this while battling juvenile rheumatoid arthritis that was diagnosed at the age of three.

Mikayla is a courageous young lady who has chosen not to let this frequently debilitating disease control or limit her life. She has also chosen to be an active advocate for the Arthritis Foundation. Besides coming to Washington, D.C. to encourage Congress to increase funding for arthritis research, she has also raised money for that research herself by participating in the Orange County Foundation Arthritis Walk.

Mikayla, I want to thank you for your courage and for taking the time to come to Washington to share your story before this Committee. You truly are an inspiration to all of us.

Mr. OBEY. We are glad to have you here. I hope you are getting better grades in the fifth grade than I did when I was in fifth grade. [Laughter.]

Go ahead.

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WEDNESDAY, MARCH 18, 2009.

## ARTHRITIS FOUNDATION

### WITNESS

#### MIKAYLA MINNIG

Ms. MINNIG. Good afternoon. My name is Mikayla Minnig, and I live in Downey, California. I am here today on behalf of the nearly 300,000 kids like myself who have juvenile arthritis. I am 10 years old and in the fifth grade.

I was diagnosed with pauciarticular juvenile rheumatoid arthritis when I was just three years old. Pauciarticular means it affects four or fewer joints and usually large joints. For me, it affects my left knee and ankle. I also am at high risk for eye inflammation and must have them checked often so I don't become blind, which could happen.

It all began when I felt a lot of pain and swelling in my neck. I couldn't walk or run like the other kids, and I couldn't turn my head.

For many months, I went to a lot of different doctors to figure out what was wrong with me. Some of these doctors told my par-

ents I must have bad growing pains or must be faking the pain and tears. Finally, we were sent to a pediatric rheumatologist, a doctor who treats kids like me with juvenile arthritis. Dr. Starr said I had arthritis.

My parents were surprised. They didn't know, like most people, that kids got arthritis too. In fact, most people don't know that juvenile arthritis is one of the leading causes of disability in common childhood diseases in the United States.

People are surprised when I tell them I have arthritis because I don't look very different from other kids. But unlike other kids, I take a cancer drug every week plus daily medication to help control my arthritis, and it helps me try and lead a normal kid life.

I have met other kids through the Arthritis Foundation who are not as lucky as me. The drugs don't work for them, and they end up in wheelchairs or have to have joints replaced. In fact, juvenile arthritis is the leading cause of disability in kids.

I also am lucky to be able to see a doctor who understands and can treat my disease. Kids in nine States don't have a single specialist to see them.

I am here today to ask Congress to focus more attention on kids like me with arthritis. Research is the key to a cure. Research has led to newer drugs that help kids stay out of wheelchairs, but these drugs can have really bad side effects. We need a cure.

Right now, the government spends \$9,800,000 at the National Institutes of Health for juvenile arthritis research. That sounds like a lot of money to me, but when you think of the nearly 300,000 kids, that works out to be just about \$32 per child.

There is a group of pediatric rheumatologists who are working together to study and treat children with arthritis, but they need your help. With more funding and attention from Congress, more research studies can move forward to help find a cure.

The Arthritis Foundation supports at least a doubling of juvenile arthritis research over the next few years. Also, the NIH should spend more money training future doctors.

Thousand of kids around the country are diagnosed too late to prevent damage. Please help change this.

I hope one day when I tell people I got arthritis at age three and they say, but kids don't get arthritis, I can tell them, you are right, not any more because research has found a cure.

Thank you for the opportunity to speak to you today.

[The information follows:]

Mikayla May Minnig  
Child with Juvenile Rheumatoid Arthritis  
Downey, California  
Wednesday, March 18, 2009  
10:00 AM  
Arthritis Foundation

**Summary:**

46 million adults and 294,000 children are living daily with arthritis in the United States. Juvenile arthritis is the leading cause of acquired disability in children and is the sixth most common childhood disease. The Arthritis Foundation supports, at least, a doubling of juvenile arthritis research over the next few years from the current funding of \$9.8 million at the National Institutes of Health. In addition to addressing the critical shortage of pediatric rheumatologists (195 currently practicing in the U.S.), the NIH could leverage its public research funds through the Childhood Arthritis and Rheumatology Research Alliance's capabilities to support a national network of cooperating clinical centers for the care and study of children with arthritis. Such collaboration increases the number of children who participate in studies and reduces the research time it takes to reach valuable conclusions.

**Testimony of Mikayla Minnig on behalf of the Arthritis Foundation  
Submitted to the House Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies  
March 18, 2009**

My name is Mikayla Minnig, and I live in Downey, California. I am here today on behalf of the nearly 300,000 kids like myself who have juvenile arthritis. I am 10 years old and in the 5<sup>th</sup> grade. I was diagnosed with pauciarticular juvenile rheumatoid arthritis when I was just 3 years old. Pauciarticular means it affects four or fewer joints and usually large joints. For me, it affects my left knee and ankle. I also am at high risk for eye inflammation and must have them checked often so I don't become blind, which could happen. It all began when I felt a lot of pain and swelling in my neck. I couldn't walk or run like the other kids, and I couldn't turn my head.

For ten months I went to lots of different doctors to figure out what was wrong with me. Some of these doctors told my parents I must have bad growing pains or must be faking the pain and tears. Finally, we were sent to a pediatric rheumatologist—a doctor who treats kids like me with juvenile arthritis. Dr. Starr said I had arthritis. My parents were surprised. They didn't know, like most people, that kids got arthritis. In fact, most people don't know that juvenile arthritis is one of the most common childhood diseases in the United States.

People are surprised when I tell them that I have arthritis because I don't look very different than other kids. But unlike other kids, I take a cancer drug every week plus daily medication to control my arthritis, and it helps me try and lead a normal kid-life. I have met other kids through the Arthritis Foundation who are not as lucky as me. The drugs don't work for them, and they end up in a wheelchair or have to have their joints replaced. In fact, juvenile arthritis is the leading cause of disability in kids. I also am lucky to be able to see a doctor who understands and can treat my disease. Kids in 9 states don't even have a single specialist to see them.

I am here today to ask Congress to focus more attention on kids like me with arthritis. Research is the key to a cure. Research has led to newer drugs that help kids stay out of wheelchairs, but these drugs can have really bad side effects. We need a cure! Right now, the government spends \$9.8 million at the National Institutes of Health for juvenile arthritis research. That sounds like a lot of money to me but when you think of the nearly 300,000 kids that works out to be just about \$32 per child.

There is a group of pediatric rheumatologists who are working together to study and treat children with arthritis, but they need your help. With more funding and attention from Congress, more research studies can move forward to help find a cure. The Arthritis Foundation supports, at least, a doubling of juvenile arthritis research over the next few years. Also, the NIH should spend more money training future doctors. Kids around the country are diagnosed too late to prevent damage – please help change this. I hope one day when I tell people I got arthritis at age 3, and they say “but kids don't get arthritis” I can tell them “you are right – not any more – because research has found a cure”.



Juvenile arthritis is the leading cause of acquired disability in children and is the sixth most common childhood disease (following asthma, congenital heart disease, cerebral palsy, diabetes and epilepsy). Sustaining the field of pediatric rheumatology is essential to the care of the 294,000 children under the age of 18 living with a form of juvenile arthritis. Children who are diagnosed with juvenile arthritis will live with this chronic and potentially disabling disease for their entire life. Therefore, it is imperative that children are diagnosed quickly and treated with the most effective treatment protocols known for their particular disease.

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) is a national organization of pediatric rheumatologists who have joined together to answer critical clinical research questions. CARRA has created a multi-center network of pediatric rheumatology research centers across North America that is working together on clinical investigations. Such collaboration increases the number of children who participate in studies and reduces the research time it takes to reach valuable conclusions.

Similar research networks have dramatically advanced the treatment currently available for both childhood cancer and cystic fibrosis. Children with cancer who are treated in a participating center with network protocols now have a much greater chance of disease-free survival, compared to children treated outside the network with non-network protocols. This dramatic improvement in treatment is a direct result of careful clinical studies and trials within the collaborative research organization. The pediatric oncology networks were started 30 years ago with the goal of developing and refining treatment protocols for children with cancer in the U.S. Currently over 90% of all children with cancer in the U.S. are enrolled in a Children's Oncology Group (COG) protocol. As a result, the standard-of-care for pediatric oncology patients has been critically and comprehensively evaluated and standardized, leading directly to better outcomes with improved survival and decreased treatment morbidity. CARRA's overall goal is that by 2012 there will be a protocol for every child with a rheumatic disease to participate in. Through participation in research and conducting investigations of these diseases, we will be able to significantly improve the standard-of-care for all children with rheumatic diseases in the future.

Pediatric rheumatology is one of the smallest pediatric subspecialties with only 195 pediatric rheumatologists actively practicing in the United States. Over 95% of all pediatric rheumatologists practice in academic medical centers; however, more than one-third of U.S. medical schools do not have any pediatric rheumatology program. Over a third of pediatric rheumatologists are in single-person divisions, resulting in significant isolation. Further, there is a significant manpower deficit in pediatric rheumatology such that only one-third of all children with rheumatic diseases are cared for by a pediatric rheumatologist, and the estimated number of pediatric rheumatologists required to provide optimal care is almost twice the current number. All these factors result in lack of access to state-of-the-art subspecialty care and the opportunities for participation in research protocols for children with rheumatic diseases. One of the goals of the pediatric rheumatology research network is to offer participation in research protocols for patients of community physicians in areas where there are no pediatric rheumatologists.

The Arthritis Foundation has given substantial financial support to the development of the Childhood Arthritis and Rheumatology Research Alliance (CARRA). **However, in addition, NIH has a unique opportunity to leverage its public research funds through CARRA's**

**capabilities, and the Arthritis Foundation urges Congress to express support for a national network of cooperating clinical centers for the care and study of children with arthritis.**

While new treatment options are available, we are still working to improve the quality of life for Americans living with arthritis, and ultimately finding a cure. Research funded by the National Institutes of Health and the Arthritis Foundation has produced a revolutionary class of biological therapies that alleviate painful inflammation and prevent disability. While these advances have changed the lives of Americans living with arthritis significantly, there is still no cure for the disease and its prevalence and impact continues to grow.

The Arthritis Foundation firmly believes research holds the key to tomorrow's advances and provides hope for a future free from arthritis pain. From its inception in 1948, a core mission of the Arthritis Foundation is to raise funds each year to support peer-reviewed research. As the largest non-profit contributor to arthritis research, the Arthritis Foundation fills a vital role in the big picture of arthritis research. Our research program complements government and industry-based arthritis research by focusing on training new investigators and pursuing innovative strategies for preventing, controlling and curing arthritis. To date, the Arthritis Foundation has funded more than 2,200 researchers with more than \$380 million in grants. By supporting researchers in the early stages of their careers, the Arthritis Foundation makes important initial discoveries possible that lead to ultimate breakthrough results. However, even with this commitment every year grants that rate "stellar" in our peer review process go unfunded. These are potential cures without the funding to be realized.

An increased public investment in biomedical research holds the real promise of improving the lives of millions of Americans with arthritis. This investment will reduce the burden of arthritis on the U.S. economy with less missed work days, disability payments, and expensive surgical interventions. To illustrate this point, less than 50% of working age adults with rheumatoid arthritis are still employed 10 years after disease onset. Nearly 2/3 of people diagnosed with arthritis are *under* the age of 65. 992,100 hospitalizations and 44 million outpatient visits annually are due to arthritis.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. Research opportunities at NIAMS are being curtailed due to the stagnating and in some cases declining numbers of new grants being awarded for specific diseases. The training of new investigators has unnecessarily slowed down and contributed to a crisis in the research community where new investigators have begun to leave biomedical research careers in pursuit of other more successful endeavors.

The Arthritis Foundation is dedicated to finding a cure for arthritis. However, the investment in NIH research is absolutely crucial to realize this dream. With continued and increased investment in research, the Arthritis Foundation believes a cure is on the horizon. **The Arthritis Foundation urges Congress to increase funding and provide \$500 million for arthritis research over the next five years to continue to fuel innovation and discoveries that could put an end to the pain of arthritis.**

The medical and societal impact of arthritis in the United States is staggering. Arthritis costs the economy **\$128 billion**, which was equivalent to 1.2% of the U.S. gross domestic product in 2003. These costs include \$81 billion in direct costs for expenses like physician visits and surgical interventions, and \$47 billion in indirect costs for missed work days. Arthritis is the most common cause of disability in the United States, and nearly one-third of adults with arthritis experience work limitations.

The Arthritis Foundation strongly believes that in order to prevent or delay arthritis from impacting people and to mitigate the effects of arthritis that an investment both from the private and public sector must be made today. Research shows that the pain and disability of arthritis *can* be decreased through early diagnosis and appropriate management, including evidence based self-management activities such as weight control and physical activity. The Arthritis Foundation's Self-Help Program, a group education program has been proven to reduce arthritis pain by 20% and physician visits by 40%. These interventions are recognized by the Centers for Disease Control and Prevention to reduce health care expenditures. The Arthritis Foundation offers and partners with other organizations to offer the Self-Help Program, and an Aquatic Program, and an Exercise Program as part of our Life Improvement Series. Each of these programs is proven to reduce pain and physician visits, decrease stiffness and increase function.

The public sector investment at the federal government level entails the Centers for Disease Control and Prevention's arthritis program. In early 1998, the Arthritis Foundation joined forces with the CDC to develop the National Arthritis Action Plan – an innovative public health strategy. Among the goals are improving the scientific information base on arthritis, increasing awareness that arthritis is a national health problem, and encouraging more individuals with arthritis to seek early intervention and treatment to reduce pain and disability. Due to the Subcommittee's support and leadership, the CDC was provided with \$10 million in Fiscal Year 1999 to begin to make this vision a reality. More than ten years later, the CDC's arthritis program has not kept pace and in fact, has seen a decline in funding from just a few years ago. For Fiscal Year 2009, the arthritis program was funded at \$13.2 million.

Approximately half of the CDC's arthritis program funding was distributed through a competitive grant process to 12 state health departments. These state health departments in partnership with other state organizations have successfully used CDC funding to increase public awareness of the burden of arthritis and increase the availability of interventions that have been proven to improve the quality of life and health care of people with arthritis. Last year, twenty-eight additional states submitted grants and were approved, but unfunded due to limited funding. The CDC estimates 67 million or 25% of the adult population will have arthritis by 2030. More than 57% of adults with heart disease and more than 52% of adults with diabetes also have arthritis. Arthritis limits the ability of people to effectively manage other chronic diseases. It is time to make a significant investment now to sustain and improve the reach of these proven interventions.

**The Arthritis Foundation strongly recommends Congress appropriate \$23 million in Fiscal Year 2010 for CDC's arthritis program, which is equivalent to 50 cents per person with arthritis. This is a \$10 million increase from Fiscal Year 2009, which will ensure that qualified, participating states can continue the vital work of lessening the burden of arthritis on Americans and the American work force.**

The Arthritis Foundation greatly appreciates the opportunity to submit testimony in support of increased funding for arthritis research at the National Institutes of Health and arthritis public health initiatives at the Centers for Disease Control and Prevention, which are aimed at improving the lives of 46 million adults and 294,000 children living daily with arthritis in the United States.

**Mikayla May Minnig**

Mikayla is 10 years old and is in the fifth grade at Trinity Christian School. For six years, she has been a Girl Scout and also participates on the cheerleading squad. After ten months of pain and barely able to move, Mikayla was diagnosed with pauciarticular juvenile rheumatoid arthritis when she was 3 years old.

Mikayla is an advocate with the Arthritis Foundation. She has participated in and raised funds annually for the Orange County Arthritis Foundation Walk, attended the 2008 and 2009 Advocacy and Kids' Summit in Washington, D.C., and attended the Arthritis Foundation Southern California Chapter's juvenile arthritis summer camp at the Painted Turtle.

Mikayla resides in Downey, California with her parents, Michael and Janet Minnig.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

Mikayla May Minnig  
9345 Hasty Ave.  
Downey, CA 90240  
562-923-5883

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Arthritis Foundation

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

The Arthritis Foundation has been the recipient of a grant from the Centers for Disease Control and Prevention.

Grant Number 1 U58 DP000607-01

National Programs to support arthritis

Project Title: Implementation Strategies to Increase Arthritis/Specific Evidence Based Programs.

Budget period 10/1/06-9/30/07--\$736,000

Budget period 10/1/07-9/30/08--\$764,517

Budget period 10/1/08-9/30-09--\$619,249

Signature:

Mikayla Minnig

Date:

3/13/09

Mr. OBEY. Thank you. [Applause.]

Thank you very much for sharing your story with us.

Next is Dr. Schraufnagel, TB Coalition.

We are sorry about the order that we put you in. You get extra points for that. [Laughter.]

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WEDNESDAY, MARCH 18, 2009.

## **TB COALITION**

### **WITNESS**

#### **DR. DEAN SCHRAUFNAGEL, M.D.**

Dr. SCHRAUFNAGEL. That is a tough person to follow.

I am Dean Schraufnagel. I am a professor of medicine in the Department of Pulmonary and Critical Care Medicine at the University of Illinois in Chicago.

And, for Congressman Obey, I grew up in Mason, Wisconsin, a town of only about 65 people these days.

Mr. OBEY. They vote right. [Laughter.]

Dr. SCHRAUFNAGEL. I also serve as Vice President of the American Thoracic Society, and I am here to speak on behalf of the TB Coalition which is a network of public health research professional and advocacy organizations working to support policies to eliminate tuberculosis in the United States and around the world.

There are three points I want to make: First, tuberculosis is a problem in the United States. Second, we will never defeat tuberculosis until we develop new diagnostic tools, anti-tuberculosis drugs and an effective vaccine. Third, Congress passed an historic law reauthorizing the Nation's domestic TB program. Appropriate funding of this law will put the U.S. back on the right path toward tuberculosis elimination.

As you know, TB is an airborne infection caused by a bacterium. It is spread by cough, so that we are all vulnerable.

It is the second leading global cause of death for infectious disease, claiming about 1.7 million lives per year. It is estimated that nine to fourteen million Americans have latent tuberculosis. According to a February, 2008, World Health Organization report, resistant TB accounts for about 5 percent of all new TB cases in the world.

Although drugs, diagnostics and vaccines for TB exist, these technologies are antiquated. The most commonly used TB diagnostic in the world, sputum microscopy, is more than 100 years old and lacks the sensitivity in many HIV/TB cases and in children.

Current diagnostic tests to detect drug resistance take at least one month to complete and in that time the TB can spread to others.

The TB vaccine, BCG, provides some protection to children but has little effect in preventing adult pulmonary tuberculosis.

There is an urgent need for new anti-TB treatments and particularly for a shorter drug regimen. There is also a critical need for drugs that can safely be taken concurrently with the anti-retroviral drugs used for HIV. The good news is that these drugs are in de-

velopment and hold promise for shortening TB from six to nine months to two to four months.

In the United States, TB cases continue to decline, although the progress has slowed in the last few years.

Foreign-born and ethnic minorities bear a disproportionate burden of the domestic TB rate. U.S.-born blacks make up almost half, 45 percent, of all TB cases among U.S.-born. Border States and States with high immigration such as California, Texas and New York are among the highest burdened TB States.

Drug resistance poses a particular challenge to domestic TB control due to the high costs and intensive treatment required. The costs for treating drug-resistant tuberculosis may range from \$100,000 to \$300,000 per case, which can be a significant strain on the State public health budget. In-patient costs have been estimated by the California XDR for extremely drug resistant TB to be up to \$600,000 per patient.

The U.S. Public Health Service has the expertise to eliminate TB, but many State programs are seriously under-resourced.

In recognition of the need to strengthen domestic TB control, Congress passed the Comprehensive Tuberculosis Elimination Act of 2008. This historic legislation was based on the recommendations of the Institute of Medicine to revitalize the CDC and NIH programs. We recommend that you give the full level of \$210,000,000 in fiscal year 2010 for CDC's Division of Tuberculosis Elimination as authorized by the Comprehensive TB Act.

In conclusion, Mr. Chairman, the U.S. stands on the brink of being able to eliminate tuberculosis. What is needed is U.S. leadership to reduce the global pandemic as called for by the Lantos-Hyde Leadership Against AIDS, TB and Malaria Act and the appropriate allocations of resources for domestic TB control and research that are called for in this Act.

Thank you.

[The information follows:]



**STATEMENT OF  
THE TB COALITION**

**Presented by Dean Schraufnagel, MD  
Professor of Medicine, Department of Pulmonary, Critical Care and Sleep Medicine  
at the University of Illinois at Chicago**

**submitted to**

**THE HOUSE LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION  
APPROPRIATIONS SUBCOMMITTEE**

**on the**

**FISCAL YEAR 2010 LABOR, HEALTH AND HUMAN SERVICES, AND  
EDUCATION APPROPRIATIONS BILL**

**March 18, 2009, 10:00a.m.**

**Department of Health and Human Services  
Summary of Programs**

**Centers for Disease Control and Prevention FY10 Funding Recommendation:  
\$8.6 Billion**

**National Tuberculosis Elimination Program  
Division of TB Elimination FY10 Funding Recommendation: \$210 Million**

**National Institutes of Health FY10 Funding Recommendation: \$32.439 Billion  
National Institutes of Allergy and Infectious Disease FY10 Funding  
Recommendation: \$5.032 Billion  
Fogarty Center FY10 Funding Recommendation: \$73 Million**

**Tuberculosis**

The TB Coalition is a network of public health, research, professional and advocacy organizations working to support policies to eliminate TB in the U.S. and around the world. The TB Coalition is pleased to submit our recommendations for programs in the Labor-Health and Human and Education purview. **The TB Coalition, in collaboration with Stop TB USA, recommends a funding level of \$210 million in FY 2010 for CDC's Division of TB Elimination, as authorized under the Comprehensive TB Elimination Act.**

### **TUBERCULOSIS**

Tuberculosis (TB) is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis*. TB primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine. TB is the second leading global infectious disease killer, claiming 1.7 million lives each year. Currently, about a third of the world's population is infected with the TB bacterium. It is estimated that 9-14 million Americans have latent TB. Tuberculosis is the leading cause of death for people with HIV/AIDS in the developing world. According to a February 2008 World Health Organization (WHO) report on drug resistant TB, about 5% of all new TB cases are drug resistant. The global TB pandemic and spread of drug resistant TB present a persistent public health threat to the U.S.

The major factors that have caused the spread of drug resistant TB, including multi-drug resistant TB (MDR) and extensively drug resistant (XDR) TB, are inadequate attention to and funding for basic TB control measures in high TB burden, resource-limited settings, which also have high HIV prevalence, and the lack of investment in new drugs, diagnostics and vaccines for TB. While most TB prevalent today is a preventable and curable disease when international prevention and treatment guidelines are used, many parts of the world, such as Africa and Eastern Europe, are struggling to implement them, giving rise to more drug resistant TB, and, increasingly, XDR-TB.

### **XDR-TB as a Global Health Crisis**

XDR-TB has been identified in all regions of the world, including the U.S. The strain is resistant to two main first-line drugs and to at least two of the six classes of second-line drugs. Because it is resistant to many of the drugs used to treat TB, XDR-TB treatment is severely limited and the strain has an extremely high fatality rate. In an outbreak in the KwaZulu-Natal province of South Africa from late 2005 until early 2006, XDR TB killed 52 out of 53 infected HIV-infected patients within just three weeks of diagnosis.

### **New TB Tools Needed**

Although drugs, diagnostics, and vaccines for TB exist, these technologies are antiquated and are increasingly inadequate for controlling the global epidemic. The most commonly used TB diagnostic in the world, sputum microscopy, is more than 100 years old and lacks sensitivity to detect TB in most HIV/AIDS patients and in children. Skin tests used in the U.S. are more effective at detecting TB, but take one to six weeks to culture in a laboratory. Current diagnostic tests to detect drug resistance take at least one month to complete. Faster drug susceptibility tests must be developed to stop the spread of drug resistant TB. The TB vaccine, BCG, provides some protection to children, but it has little or no efficacy in preventing pulmonary TB in adults.

There is an urgent need for new anti-TB treatments, and particularly for a shorter drug regimen. Currently, the drug regime for TB treatment is 6-9 months. A shorter drug regimen with new classes of drugs active against susceptible and drug-resistant strains would increase compliance, prevent development of more extensive drug resistance, and save program costs by reducing the time required to directly observe therapy for patients. There is also a critical need for drugs that can safely be taken concurrently with

antiretroviral therapy for HIV. The good news is that new drugs in development hold the promise of shortening treatment from 6-9 months to 2-4 months.

#### **TB in the U.S.**

Although the numbers of TB cases in the US continue to decline, with 12,898 new cases reported in 2008, progress towards TB elimination has slowed. The average annual percentage decline in the TB rate slowed from 7.3% per year during 1993--2000 to 3.8% during 2000--2008. Foreign-born and ethnic minorities bear a disproportionate burden of U.S. TB cases. The proportion of TB cases in foreign-born people has increased steadily in the last decade, from 27 percent of all cases in 1992 to 58 percent of all cases in 2008. Border states and states with high immigration levels such as California, and Texas and New York are among the highest-burdened TB states. U.S.-born blacks make up almost half (45%) of all TB cases among U.S.-born persons.

In the 1970s and early 1980s, the U.S. began significantly reducing the TB control infrastructure. Consequently, the trend towards TB elimination was reversed and the nation experienced an unprecedented resurgence of TB, including many MDR-TB cases, with a 20% increase in cases reported between 1985 and 1992. In just one city, New York City, the cost to regain control of TB was over \$1 billion. The 2000 Institute of Medicine (IOM) report, *Ending Neglect: the Elimination of Tuberculosis in the United States*, found that the resurgence of TB in the U.S. between 1985 and 1992 was due, in large part, to funding reductions and concluded that, with proper funding, organization of prevention and control activities, and research and development of new tools, TB could be eliminated as a public health problem in the U.S.

Drug-resistant TB poses a particular challenge to domestic TB control owing to the high costs of treatment and intensive health care resources required. Treatment costs for multidrug-resistant (MDR) TB range from \$100,000 to \$300,000, which can cause a significant strain on state public health budgets. Inpatient care has been estimated for California XDR TB patients from 1993-2006 at an average of approximately \$600,000 per patient.

#### **Strong State and Local TB Control Programs**

The best defense against the development of drug resistant tuberculosis is a strong network of state and local public health programs and laboratories. State, local, and territorial health departments provide important TB control services such as directly observed therapy (DOT, a proven method to improve adherence and thus prevent drug resistance), laboratory support, surveillance, contact tracing, and patient counseling. CDC provides about \$100 million annually in support to state, local and territorial health departments to prevent and control TB.

According to the National Tuberculosis Controller's Association, for every confirmed case of TB, state and local health department must identify and test an estimated 14 persons who may have been exposed. Yet after almost a decade of stagnant funding, many state TB programs have been left seriously under-resourced at a time when TB cases are growing more complex to diagnose and treat. The higher percentage of foreign-

born TB patients adds to the need for specially trained TB professionals. According to a recent assessment by CDC's Div. of TB Elimination, more than 1077 jobs have been lost in state TB control programs over the last three years, ranging from doctors and nurses to lab personnel and outreach workers.

Despite low rates, persistent challenges to TB control in the U.S. remain. Specifically: (1) racial and ethnic minorities continue to suffer from TB more than majority populations; (2) foreign-born persons are adversely impacted; (3) sporadic outbreaks/clusters occur, outstripping local capacity; (4) continued emergence of drug resistance threaten our ability to control TB; and (5) there are critical needs for new tools for rapid and reliable diagnosis, short, safe, and effective treatments, and vaccines.

#### **Congressional Response to TB**

In recognition of the need to strengthen domestic TB control, the Congress passed the Comprehensive Tuberculosis Elimination Act (CTEA) (P.L. 110-392) in October, 2008. This historic legislation was based on the recommendations of the Institute of Medicine and revitalized programs at CDC and the NIH with the goal of putting the U.S. back on the path to eliminating TB. The new law authorizes an urgently needed reinvestment into new TB diagnostic, treatment and prevention tools. **The TB Coalition, in collaboration with Stop TB USA, recommends a funding level of \$210 million in FY 2010 for CDC's Division of TB Elimination, as authorized under the CTEA.** The CTEA as introduced included a separate authorization of \$100 million through CDC's TB elimination program for the development of urgently needed new TB diagnostic, treatment and prevention tools to ease the global TB pandemic, and we hope that this unique area of need will be considered in the final FY10 funding levels.

#### **National Institutes of Health**

The NIH has a prominent role to play in the elimination of tuberculosis through the development of new tools to fight the disease, however the ATS is concerned that the NIH has reduced funding for TB research from \$211 million in 2007 to \$160 million in 2008. We encourage the NIH to expand efforts, as requested under the Comprehensive TB Elimination Act, to develop new tools to reduce the rising global TB burden, including faster diagnostics that effectively identify TB in all populations, new drugs to shorten the treatment regimen for TB and combat drug resistance, and an effective vaccine.

#### **Fogarty International Center TB Training Programs**

The Fogarty International Center (FIC) at National Institutes of Health (NIH) provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area of TB treatment and research. These training grants should be expanded and offered to all institutions. **The ATS recommends Congress provide \$73 million for FIC in FY2010, which would allow the expansion the TB training grant program from a supplemental grant to an open competition grant.**

The global TB epidemic endangers TB control efforts in the U.S. TB case rates in the United States reflect the global situation. The best way to prevent the future development of drug-resistant strains of tuberculosis is through establishing and supporting effective global and domestic tuberculosis control programs and research programs through the U.S. Agency for International Development (USAID), the CDC and the NIH. The TB Coalition appreciates this opportunity to provide testimony.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

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Your Name, Business Address, and Telephone Number: Dean Schraufnagel, MD University of Illinois at Chicago 840 S Wood Street, Room 920-N cSB, MC 719 Chicago, IL 60612 312-996-8039
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.  TB Coalition American Thoracic Society
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?  <p align="center"><u>Yes</u>      No</p>
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.  1. Dean Schraufnagel, MD - National Institutes of Health Phase II/III clinical trial HHSN268200617187C <i>Sildenafil Therapy in Patients with Sickle Cell Disease and Pulmonary Hypertension</i> Total award: \$707,004.00  1) American Thoracic Society (ATS) – Department of Energy – UT Battelle, ATS Statement on Beryllium Disease Total award: \$19,484.00  2) ATS – CDC - National Institute for Occupational Safety and Health – Chronic Beryllium Disease Total award: \$10,000.00  3) ATS - National Heart, Lung and Blood Institute – PATS Supplemental Sponsorship Total Award: \$10,000.00  4) ATS - U.S. Agency for International Development – TB Coalition for Technical Assistance, International Standards for TB Care Total award: \$1,263,968.00

Signature: Dean Schraufnagel      Date: Mar 18, 2009

Mr. OBEY. Thank you very much. We appreciate your testimony. Next, Mr. Neil Horikoshi, Aplastic Anemia and MDS International Foundation.

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WEDNESDAY, MARCH 18, 2009.

**APLASTIC ANEMIA AND MDS INTERNATIONAL  
FOUNDATION**

**WITNESS**

**NEIL HORIKOSHI**

Mr. HORIKOSHI. Good afternoon and thank you very much for the opportunity, Chairman Obey and Ranking Member Tiahrt.

Most of the people in this room today have probably never heard of bone marrow failure disease, let alone the words, aplastic anemia, myelodysplastic syndromes, as well as PNH. But this strikes home very close to Congress as these diseases have hit members of your family, including Congressman Joe Moakley and Congressman Bob Matsui.

So, for me, I am affiliated with this organization, the Aplastic Anemia and MDS International Foundation as Chair in part because I am an aplastic anemia patient myself, and I came within 48 hours of death. In my darkest hours, I looked exactly like this.

If you think about your colleagues and what happened just before Christmas of 2004, Congressman Bob Matsui was in his office. On January 1, 2005, he passed away. He looked like me. He looked exactly like me. He went to the office.

So what happened?

What happens is it happens inside of one's body. Bone marrow fails. You fail to produce blood. And I am going to explain what that means for the various diseases.

In my case, it was all about taking the last physical, getting a blood exam and finding out I didn't have any blood in me. That is coming very close. So, hence, I dedicate myself to supporting this organization and what bone marrow failure means to other Americans.

Aplastic anemia is the condition where one's body is not able to produce any blood. MDS, which is what Bob Matsui and Joe Moakley had, are the conditions where they were able to produce some blood, but the blood was defective. And PNH is the condition where you are able to produce blood, but your immune system ends up destroying that blood.

These are all very, very rare diseases often called orphan diseases, in a nutshell. So, hence, there hasn't been much focus on the topic overall. Roughly, 20,000 to 30,000 Americans get these types of diseases each year.

One of the things that I will ask for, and I know it is not within the jurisdiction of this Subcommittee, but I would ask all members sitting before me today to look at H.R. 1230, the Bone Marrow Failure Disease and Treatment Act of 2009 which increases the surveillance efforts at CDC and also creates a Bone Marrow Failure Registry. This legislation was introduced by Congresswoman Doris

Matsui after she lost her husband, and I am sure your colleague and friend, Bob Matsui.

I would also ask this Subcommittee to seriously consider the appropriate appropriations once this bill is passed.

And I also urge this Subcommittee to continue to focus on its ongoing research to NIH because but for the work that individuals such as Dr. Neal Young, who did the necessary work some years ago to find at least treatment for aplastic anemia, I really wouldn't be here in front of you today. Twenty-five years ago when our organization was founded, the death rate of anyone with aplastic anemia was 100 percent. One hundred percent.

Fifteen years ago, had I received this disease, it was still about 50 percent. I am one of the lucky few that made it through in the 50 percent. So ongoing funding to NIH is extremely important to us.

Lastly, I ask that the full Appropriations Committee continue to be very cognizant of the work that is going on for the Bone Marrow Failure Disease Research Program that DOD has embarked upon and to fund this program to the increased funding of \$7,500,000 from \$5,000,000 today.

Thank you very much.

[The information follows:]



**Testimony before the Public Witness Hearing, March 18, 2009  
House Appropriations Subcommittee on  
Labor-Health and Human Services-Education  
by  
Neil Horikoshi, Chairman of the Board  
Aplastic Anemia & MDS International Foundation**

Thank you, Mr. Chairman and members of the subcommittee, for giving me the opportunity to testify today. Many of you have probably never heard of aplastic anemia or some of the other diseases that are collectively known as “bone marrow failure diseases.” I certainly had never heard of these diseases prior to February 29, 2000. That day, however, would prove fateful for me and change my life in a way I could not have foreseen. And over a critical 48 hour stretch, I would descend from a level of seemingly perfect health to the precipice of death. I would soon learn firsthand how a rare, deadly bone marrow failure disease can strike anyone, regardless of age or state of general health.

In 2000, I was on international assignment with IBM in Japan, and I traveled quite frequently for this job. Prior to a scheduled trip to India, I was feeling exceptionally fatigued. I also started to suffer from a shortness of breath, constant chills, and tingling in his fingers and toes. I even noticed red splotches on both of my calves.

These symptoms should have set off sirens and whistles in any person. Yet, as a healthy 40+ year old male who exercised and ate well, I shrugged it off. “Maybe I should get more exercise, or more sleep, or take some vitamins,” I recall saying to myself at the time.

If I had not had a regularly scheduled physical examination prior to this trip -- the last available Saturday appointment at a clinic in Tokyo -- I may never have made it alive to India. My fortuitous decision to keep my appointment led to a series of steps that would determine my ultimate diagnosis and the treatment that would save my life.

At my physical, the medical doctor ordered a Complete Blood Count (CBC) immediately, and noticed all the telltale symptoms of a serious medical condition. The next day --- the day before my scheduled trip -- I experienced worsening symptoms. I began to have blurred vision in my left eye due to a small hemorrhage behind my retina. My doctor called me that day and clearly stated: “cancel your trip to India. ...your blood counts are unusually low.” Fortunately, I listened to the advice of my doctor.

The blood specialist at the local hospital in Japan conducted another CBC, and he reconfirmed that I had a serious blood shortage. His best guess diagnosis was that I might have leukemia. I was given a blood transfusion, sufficient to put me on a flight to Honolulu for further treatment.

In a classic case of “good news, bad news,” the hematologist in Hawaii informed that I did not have leukemia. The bad news was that I was diagnosed with a rare bone marrow failure disease known as **aplastic anemia**, which in laymen’s terms meant that my bone marrow was not producing any blood.

I had no idea what this diagnosis meant, what the treatment was, or how I contracted the disease. As I would later discover, the causes of aplastic anemia and other bone marrow failure diseases are unknown. Bone marrow failure disease has been linked to environmental factors to which we are all commonly exposed. Researchers suspect that undefined genetic factors make some individuals more susceptible to bone marrow disease.

My treatment in the short term consisted of getting ongoing CBC’s to monitor my blood counts. As the red and platelet blood counts dropped into a trough range, I required ongoing blood transfusions of both red and platelet blood. (Red blood cells support the flow of oxygen in one’s body; platelets support positive healing of all wounds and bleeding; white blood cells are required to fight infections, and one’s body must be able to produce these cells.)

Long term options were somewhat less clear.

I was advised that I was too old for a bone marrow transplant. A 40+ year old patient requires the anti-thymocyte globulin (ATG) treatment. My family doctor told me it may be wise to ‘get your things in order.’ Those were five words that shaped my choice in the weeks and months ahead.”

Like many Americans who are diagnosed with a rare disease, I turned to the Internet for information about treatment options and support networks. I discovered a unique resource and positive voice of reinforcement in the Aplastic Anemia & MDS International Foundation. The organization provided me with an abundance of patient-friendly information and a network of medical doctors who could provide answers to basic and personal questions about the treatment I faced.

The Foundation also directed me to Dr. Neal Young, the pre-eminent expert on aplastic anemia at the National Institutes of Health (NIH). Dr. Young pioneered research in this orphan disease, and his success with immunosuppressant treatments literally saved my life and the lives of many others.

By the end of March, 2000, within a month of my initial diagnosis, I was treated with ATG in a local Honolulu hospital. I was not transfusion free until May, 2000 when my blood counts stabilized and I slowly began to produce blood. I returned to my job in August 2000 and felt I was a very lucky person. In January 2001, I showed signs of relapsing and got a second ATG treatment in Hawaii, and within a week, my blood counts shot up to the normal levels they are at today.

What I learned from my medical consultations with Dr. Young, and my interaction with the Foundation, was that I had hope. Not more than a decade ago, most people diagnosed with acute aplastic anemia had little chance of survival. Today the success and survival rate is viewed positively, thanks in large part to the research funded by NIH

While many advances have been made in the understanding and treatment of bone marrow failure diseases, we still do not have a cure. Every year, more than 20,000 Americans are diagnosed with aplastic anemia, myelodysplastic syndromes or PNH – the three primary bone marrow failure diseases. We still do not have a good handle on what causes these diseases, and why some groups, such as ethnic Asians, are affected more than others.

My life was saved thanks to medical research – and today I want to use my story to help save the lives of others who are affected by this terrible disease. Today, I serve as the Chairman of the Board of the Foundation, and am committed to advocating for greater research and awareness that will ultimately lead to a cure.

I therefore urge the Labor-HHS-Education Subcommittee to commit greater resources to NIH and the Centers for Disease Control and Prevention. I also urge every member of this committee to support H.R. 1230, the Bone Marrow Failure Disease Research and Treatment Act, to increase surveillance efforts at CDC so that we can truly understand what is causing these diseases. This legislation has been introduced by Representative Doris Matsui (D-CA), who only a few years ago lost her husband – and your former colleague – Bob Matsui to MDS, one of the bone marrow failure diseases. When this legislation is enacted, I hope this committee will provide the necessary appropriations to implement better surveillance at the CDC.

Finally, I would also like to recognize the full committee for its support of bone marrow failure disease research at the Department of Defense (DoD). Although not within the jurisdiction of this subcommittee, the DoD Bone Marrow Failure Disease Research program was funded at \$5 million in fiscal year 2009. This funding will have a great impact on gaining a better understanding of these diseases, particularly within the veteran population.

Mr. Chairman, I am a very lucky person. Because of early intervention and access to critical information and support groups, I survived this awful disease. I hope that my testimony today can in some small way make a difference for everyone suffering from bone marrow failure diseases. I urge the House Appropriations Committee to continue its support for bone marrow failure disease research and surveillance at NIH, CDC and DoD.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Neil Horikoshi  
President & Executive Director  
Asian and Pacific Islander American Scholarship Fund  
1900 L Street NW, Suite 210, Washington, DC 20036  
Direct: 202-747-7234; Office: 877-808-7032  
Fax: 202-530-0643; Cell: 240-644-8555  
[nhorikoshi@apiasf.org](mailto:nhorikoshi@apiasf.org); [http:// www.apiasf.org](http://www.apiasf.org)

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

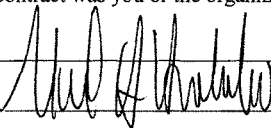
The Aplastic Anemia & MDS International Foundation

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

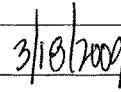
Yes      No  
NO

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

Signature:



Date:



Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you very much. We appreciate your sharing your story with us, and we wish you well.

Next, Ms. Linda Rosenberg, National Council for Community Behavioral Healthcare.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL COUNCIL FOR COMMUNITY BEHAVIORAL  
HEALTHCARE**

**WITNESS**

**LINDA ROSENBERG, MSW**

Ms. ROSENBERG. Thank you. Good afternoon, Chairman Obey and members of the Subcommittee.

My name is Linda Rosenberg, and I am the President and CEO of the National Council for Community Behavioral Healthcare.

The National Council represents 1,600 community mental health centers and safety net agencies. Collectively, they serve over six million low-income children and adults with mental health and addiction disorders.

Mr. Chairman, the public mental health system confronts twin crises. First and foremost, the mortality rates among persons with serious mental illnesses are shocking. According to a 2006 SAMHSA survey, persons with conditions like schizophrenia and bipolar disorder die, on average, 25 years sooner than other Americans. Most people with serious mental illnesses will not live to see their fiftieth birthday.

This constitutes the highest death rate among any population by any agency of the U.S. Public Health Service that receives funding from this Subcommittee. These horrific mortality rates are primarily caused by co-occurring medical illnesses: asthma, diabetes, cancer, heart disease and pulmonary conditions.

That is why, Chairman Obey, we owe you a great debt. In the appropriations legislation passed last week, you fought for the inclusion of \$7,000,000 to co-locate primary care capacity in community mental health organizations. This integrated care model will enable us to do little things like take a patient's blood pressure and big things like make sure a person who has schizophrenia and heart disease gets to see a cardiologist.

We always appreciate your willingness to both listen and to take action.

A parallel crisis we confront is the economic downturn. The State of Illinois is preparing to close 5 community mental health centers in Chicago, cutting psychiatric capacity in that city by 40 percent. In Iowa, the counties are running out of mental health dollars, and the State just announced a 6.5 percent mental health cut across the board.

And I should note that these consumers do not just disappear. Their outcomes are bad. They wind up in State mental hospitals. They wind up in nursing homes. They wind up in jails, and they wind up on the streets.

At the same time that these cuts are being enacted, community mental health centers are reporting a surge of newly unemployed

people seeking services. A survey we took indicates a 20 percent increase in psychiatric intakes. In Colorado, members are serving a record number of people, 90,000 men, women and children. In New York, providers report a 30 percent increase in demand for psychiatric treatment.

We cannot also ignore the ravages of addiction. Addiction affects one in ten Americans and one in four children. State and local governments fund half of the substance abuse treatment in this country, and the current economic downturn is resulting in addiction service reductions across the country.

While the Recovery Act was helpful to us, particularly the Medicaid policy changes, we are turning to this Committee for additional Federal support, and, specifically, we have three priorities.

First, a \$35,000,000 increase for the Integrated Mental Health Primary Care Program. As you well know, these funds help us to save lives. Furthermore, the funding increment we are asking for is consistent with the second year of funding for the Children's Mental Health Services Program, another vital program that you started.


Second, a \$100,000,000 increase for the SAMHSA Community Mental Health Services Block Grant. I should note that the block grant has not had an increase in a decade and has lost 50 percent of its purchasing power. The additional funds would flow directly to community mental health providers and States hit with budget deficits and high unemployment.

Third, a \$150,000,000 increase to the Substance Abuse Prevention and Treatment Block Grant. This increase will go a long way to ensuring that our Nation's addiction treatment system can respond to increasing demand.

We know that you are confronted with difficult choices in the 2010 appropriations cycle, but, Mr. Chairman and members, we can assure you these new dollars would be wisely spent, helping those in need and providing central primary care services to persons with serious mental illness.

We thank you for the opportunity to testify.

[The information follows:]

 **NATIONAL COUNCIL  
FOR COMMUNITY BEHAVIORAL HEALTHCARE**  
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LINDA ROSENBERG, MSW, President & CEO ELIZABETH EARLS, MA, Board Chair



**TESTIMONY OF LINDA ROSENBERG, MSW**

**PRESIDENT AND CHIEF EXECUTIVE OFFICER  
NATIONAL COUNCIL FOR COMMUNITY BEHAVIORAL HEALTHCARE  
WASHINGTON, D.C.**

**ON BEHALF OF THE NATIONAL COUNCIL FOR COMMUNITY BEHAVIORAL HEALTHCARE**

**REGARDING:**

**FY 2010 APPROPRIATIONS FOR THE SUBSTANCE ABUSE AND MENTAL HEALTH  
SERVICES ADMINISTRATION**

- **CO-LOCATION OF PRIMARY CARE WITHIN MENTAL HEALTH ORGANIZATIONS**
  - **COMMUNITY MENTAL HEALTH SERVICES BLOCK GRANT**
  - **SUBSTANCE ABUSE PREVENTION AND TREATMENT BLOCK GRANT**

**HEARING - LABOR, HEALTH, EDUCATION SUBCOMMITTEE  
MARCH 18, 2009 - 2:00 PM**



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LINDA ROSENBERG, MSW President & CEO ELIZABETH EARLS, MA Board Chair

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Good morning, Chairman Obey and members of the subcommittee. My name is Linda Rosenberg, and I am the President & CEO of the National Council for Community Behavioral Healthcare. The National Council represents 1,600 Community Mental Health Centers and other safety net community-based agencies. Collectively, they serve over 6 million low-income children and adults with mental health and addiction disorders nationwide.

**High mortality rate among public mental health clients**

Mr. Chairman, Our nation's mental health and addiction treatment systems have been underfinanced for years. This situation is currently being exacerbated by reductions in state and local funding, at the same time that more Americans are losing their health insurance, alcohol sales are at an all time high, and more and more people are in need of treatment.

The public mental health system now confronts twin crises. First and foremost, the mortality rates among persons with serious mental illnesses in the United States can only be characterized as shocking. According to a December 2006 study of eight state mental health agencies conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA), persons with illnesses like schizophrenia and bipolar disorder **die – on average – 25 years sooner** than other Americans.<sup>1</sup> As best as we can determine, this constitutes the highest death rate among ANY population served by ANY agency of the U.S. Public Health Service that receive funding from this subcommittee.

These horrific mortality rates are primarily caused by co-occurring chronic diseases. Specifically, the people we serve in the public mental health system have an extraordinarily high incidence of asthma, diabetes, cancer, heart disease and cardio-pulmonary conditions of every shape and kind. Lack of access to primary care and specialty medicine is a critical factor in explaining these terrible clinical outcomes.

There is strong evidence of the positive health impact of access to high quality, integrated care for individuals with serious mental illnesses. A randomized trial conducted by Druss<sup>2</sup> in the VA system assigned individuals living with serious mental illnesses to receive primary care either through an integrated care initiative located in mental health clinics or to the VA general medicine clinic. A multidisciplinary team worked in the integrated care clinic where a nurse practitioner provided most of the medical care, a nurse care manager provided

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patient education, liaison with behavioral health care providers, and case management services, and a family practitioner supervised the nurse practitioner and served as liaison to psychiatry and physicians in other medical services.

The model emphasized patient education, preventive services and collaboration with behavioral health providers. Individuals served in the integrated model were significantly more likely to have made a primary care visit, had a greater mean number of primary care visits, were more likely to have received 15 of 17 preventive measures, and had a significantly greater improvement in their health.

That is why, Chairman Obey, we owe a great debt to you. In the omnibus appropriations legislation that was just passed Congress last week, you fought for the inclusion of \$7 million in new SAMHSA funding to co-locate primary care capacity in Community Mental Health Centers. For the first time since the community-based mental health movement was created by President John Kennedy almost 50 years ago, CMHCs can develop the capacity to address a consumer's overall health. This integrated care model will enable us to do the little things.....like taking a patient's blood pressure, and the big things.....like arranging a cardiologist to see a consumer with schizophrenia who has heart disease.

Again, we appreciate your willingness both to listen – and take action – on behalf of people who cannot advocate for themselves.

#### **State budget cuts undermine mental health care**

A parallel crisis we confront is the economic downturn, which is placing enormous pressure on state and local budgets. A recent study compiled by the National Association of State Mental Health Program Directors Research Institute, Inc. (NRI) found that most states' mental health agencies are experiencing budget cuts in the current and next fiscal years. Thirty-two of the 42 responding State Mental Health Agencies reported that their states are experiencing budget shortfalls in both the current fiscal year (FY2009) and next fiscal year (FY2010). Thirteen of the 42 states are already expecting budget shortfalls in FY2011.<sup>3</sup>

In response to these budget shortfalls, states are reducing services, including funding for individuals who are uninsured. They are also closing programs, reducing, or freezing provider reimbursement rates, and generally reducing access to critical treatment and support services.

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For example, the State of Illinois is closing five of Chicago's 12 Community Mental Health Centers (CMHCs) – fully 40 percent of city's outpatient psychiatric capacity. In Iowa, the counties are running out of money and the state just announced a 6.5 percent across-the-board cut in services for low-income people with mental illnesses and developmental disabilities.

I should note here that these consumers do not magically disappear from our caseloads once public funding is cut. Withdrawing community-based supports for some of the most vulnerable people in American society typically results in a number of different outcomes – all of them awful: incarceration, homelessness, psychiatric emergency room visits, or placements in high cost state mental hospitals and nursing facilities.

At the very same time that our public funding is being reduced, CMHCs are reporting a surge of newly unemployed persons seeking mental health services. The National Council just completed a survey indicating a stunning 15 percent to 17 percent increase in initial psychiatric intakes. In fact, National Council members in Colorado served a record number of individuals and families in 2008 – over 90,000 men, women and children statewide. Substance abuse, anxiety, depression and the stress related to the economic downturn are contributing to requests for help. Emergency services for people who do not have healthcare benefits are also responsible for much of the increase in demand. Community providers also see a large number of National Guard members and reservists – particularly those located in rural areas – who have returned from Iraq and Afghanistan with PTSD, Traumatic Brain Injury, major clinical depression and anxiety. In short, my members are caught in a policy vise with declining state support on the one hand, and steadily increasing patient caseloads on the other.

#### **Substance Abuse Continues to Ravage Our Communities**

According to the National Institute on Drug Abuse, addiction is defined as a chronic, relapsing brain disease that is characterized by compulsive drug seeking and use, despite harmful consequences. It is estimated that substance abuse represented 1 percent of the expenditures for all healthcare in 2003. As private insurance has come to play a smaller role in financing treatment for substance use disorders -- by 2003, less than 0.5 percent of private insurance spending was allocated to it -- the share of public financing has increased -- by 2003, 77 percent of treatment for substance use disorders was publicly financed.

We cannot afford to continue to ignore the ravages of addiction. Untreated alcohol and drug addiction drains the U.S. economy of at least \$346 billion per year. Alcoholism alone is responsible for 500 million lost work days each year.

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Addiction affects one in ten Americans and one in four children. In 2007, of the 23.2 million Americans with alcohol or drug problems in 2007, only 2.4 million—roughly one in ten—received treatment at a specialty treatment facility, leaving 20.8 million untreated.

We know that prevention and early intervention strategies are critical but we fail to invest adequate resources into their development and implementation. Addiction typically begins in adolescence; research shows that the earlier a person begins to use drugs the more likely they are to progress to more serious abuse and addiction. And we know that treatment works. Over two thirds of the people with addiction do achieve recovery and treatment increases the likelihood of transitioning from use to recovery. Unfortunately, the current treatment system is insufficient and needs significant investment.

State and local governments fund half of the substance abuse treatment provided in this country – and the current economic downturn is resulting in reductions in substance abuse prevention and treatment spending across the nation. For example, of 41 states and territories responding to an inquiry by the National Association of State Alcohol/Drug Abuse Directors (NASADAD), 51.2 percent have seen a reduction in services in the past year. In states such as New York, state agencies are being forced to choose between life-saving services. With state budget cuts, the New York State Office of Alcoholism and Drug Abuse Services is being "forced to choose between the AIDS programs and its core substance abuse services".<sup>4</sup> As another example, Utah state legislators are calling for a 15 percent cut across all state agencies; resulting in about \$45 million in cuts to the Utah Department of Human Services – of which about \$30 million in cuts would be directed towards substance abuse and mental health programs in the state.<sup>5</sup>

One additional program that SAMHSA supports to improve the efficiency of the publicly-funded addiction treatment system that the National Council urges increased investment in is the Strengthening Treatment Access and Retention (STAR-SI). Through a partnership with the NIATx Resource Center at the University of Wisconsin–Madison, STAR-SI has demonstrated that process improvements can help systems reduce waste and increase efficiencies. Using NIATx principles, STAR-SI grantees are making changes that streamline processes, eliminate duplication of effort, and reduce costs across an entire payer-provider system. With regards to admissions alone, the benefit-cost-ratio for STAR-SI is 2.2, in present dollars, over the course of the grant. One STAR-SI provider stated that "[STAR-SI] is one of the best programs I've seen after several years of being in the field. I hope it continues to grow and do well."

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Therefore, while the Recovery Act is very helpful to us – particularly the Medicaid policy changes -- we are turning to this subcommittee for additional federal support. Specifically, we have two priorities:

- A \$35 million increase for the integrated mental health/primary care program. As you well know, these funds help us to save lives. Furthermore, the funding increment we are seeking is consistent with the second year of funding for the Children's Mental Health Services Program, another initiative you started in FY 1996.
- A \$100 million increase for the SAMHSA's Community Mental Health Services Block. I should note that the block grant has not received an appropriations increase in almost a decade, and has lost more than 50% of its purchasing capacity over the same time period. These additional funds would flow directly to CMHCs in states hit hard with budget deficits and high unemployment.
- A \$150 million increase to the Substance Abuse Prevention and Treatment Block Grant. This increase will go a long way in ensuring that our nation's prevention and treatment system can respond to the increasing demand.

We know that you are confronted with difficult choices in the FY 2010 appropriations cycle. But, Mr. Chairman, we can assure you that these new dollars would be employed to assist persons in psychiatric crisis and provide primary care to people in desperate need.

Thanks for the opportunity to testify today, and I am happy to answer any questions you may have.

<sup>1</sup> Mauer, B. Morbidity and Mortality in People with Serious Mental Illness. National Association of State Mental Health Program Directors Medical Directors Council. October 2006.

<sup>2</sup> Druss, B et al. Integrated medical care for patients with serious psychiatric illness. Archives of General Psychiatry, Vol 58, September 2001.

<sup>3</sup> Roberts, K. & Lutterman, T. SMHA budget shortfalls: FY 2009, 2010, & 2011. National Association of State Mental Health Program Directors Research Institute, Inc. December 2008.

<sup>4</sup> Trapasso, C. Program to help addictions in danger. New York Daily News. February 24, 2009. Available via: [http://www.nydailynews.com/ny\\_local/queens/2009/02/24/2009-02-24\\_program\\_to\\_help\\_addicts\\_in\\_danger.html](http://www.nydailynews.com/ny_local/queens/2009/02/24/2009-02-24_program_to_help_addicts_in_danger.html)

<sup>5</sup> Stryker, A. State budget cuts could cripple county substance abuse efforts. Daily Herald. January 14, 2009. Available via: <http://www.heraldextra.com/content/view/full/295821/17/>

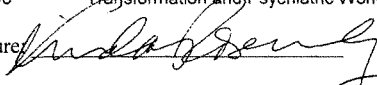
**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:	
<b>Linda Rosenberg</b> <b>National Council for Community Behavioral Healthcare</b> <b>1701 K Street, NW</b> <b>Suite 400</b> <b>Washington, DC 20006</b>	
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.	
<b>On behalf of the National Council for Community Behavioral Healthcare</b>	
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?	
Yes <b>X</b> No	
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.	
<b>All contracts are from the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services</b>	

Since 10/1/2006	Subcontractor, NASMHPD, MH Transformation		2,616
9/20/2005	Evidenced-Based Practices	HHSP233200500842P	91,607
9/7/2006	Medicaid Fact Sheets	HHSP233200600264M	2,494
9/8/2006	Deficit Reduction Act Fact Sheets	HHSP233200600211M	2,494
9/19/2006	Returning Veterans Manual	HHSP233200600937P	98,393
9/19/2006	Transformation and Psychiatric Workforce	HHSP233200600939P	76,226
9/21/2007	Transformation and Psychiatric Workforce, #2	HHSP233200700756P	93,978
7/28/2008	Performance Improvement	HHSP233200800511P	98,940
7/28/2008	Transformation and Psychiatric Workforce, #3	HHSP233200800509P	98,943

Signature:  Date: 3/17/07

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you. Just two comments, I guess.

With respect to your comments about State budgets squeezing mental health services, what I find frustrating is that whenever we have tough times, well, especially when we have tough times, we usually see a squeeze on those services. People seem to think that both of those aren't real problems, and, as you know, they are.

Secondly, I am pleased that we were able to provide the \$7 million last year.

What we are trying to do is to see that the patients are handled in an integrated manner, and I think that is fully consistent with what the Administration is talking about with respect to creating incentives in their health reform legislation that will see to it that the treatment of patients, while they are being treated, is on an integrated basis and, that there is still an after-the-event coordination as well.

Ms. ROSENBERG. We thank you so very much, all of you.

Mr. OBEY. Next, Dr. Paul Kirwin, American Association for Geriatric Psychiatry.

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WEDNESDAY, MARCH 18, 2009.

## **AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY**

### **WITNESS**

#### **DR. PAUL D. KIRWIN, M.D.**

Dr. KIRWIN. Thank you, Mr. Chairman and members of the Subcommittee, and thank you for the privilege of being here to be able to talk about the mental health needs of the elderly.

I am a practicing geriatric psychiatrist and on the Board of Directors of the American Association for Geriatric Psychiatry. I also serve as the program director for a geriatric psychiatry fellowship at Yale University School of Medicine.

As medical school faculty, I often ask my own students if they have a grandparent that is still alive, so that our teaching points can be relevant and real and personal.

As I look at the members of this Committee and the staff behind you, I wonder how many of you have an aging grandparent or parent that might need assistance one day.

Mr. OBEY. I am an aging grandparent. [Laughter.]

Dr. KIRWIN. You don't look it.

I saw patients in my clinic yesterday, one man, a decorated Korean War veteran, frozen with Parkinson's disease, now in social isolation in a nursing home, struggling with depression. I also saw another gentleman with a new onset diagnosis of prostate cancer, who also was struggling with depression. And, an 80-year-old woman who was searching to remember the names of her own children and memories that kept her life cohesive and intact, now ravished with progressive dementia.

These could be our loved ones, and maybe you have people in your family with similar ailments—a favorite raucous uncle who used to take you skiing with your cousins, a grandmother who brought you to her home for Sunday dinner, a mother who laughed and cried with joy as you stepped off a graduation podium.

These people are with us now in our lives. This is not an abstract concept.

As you know, the Baby Boom generation is nearing retirement. Shortly, there will be approximately 40 million people in the United States over the age of 65. Many estimates predict that at least 20 percent of those people will suffer with some form of mental illness in the sunset of their lives.

The economic, emotional and family costs of dealing with late life mental illness are staggering, as you know. Efforts to prevent and treat these disorders are critical to our Nation's health.

The AAGP believes that three key issues need to be addressed.

First, workforce issues. As a training director, I know how dire it is to recruit people into our field to treat people with late life mental illness. Last spring, the Institute of Medicine released a study of the Nation's health care workforce to meet the needs of an aging population which called for immediate investments in preparing our health care system to care for older Americans and their families.

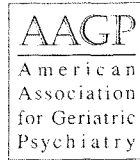
While providing vital information on many issues regarding the health care of older adults, the 2008 report didn't delve deeply into the mental health care needs. The AAGP believes that a complementary study must be undertaken to consider vital areas of concern. We have the support of the IOM for an additional study and have been advised by IOM staff that the study would cost about \$1,000,000.

Second, the lack of funding for mental health research focused on older adults. Funding for increases in the NIH and NIMH budget are critical and to have those funds focused on not just the broader mental health needs but those specifically of older Americans.

And, lastly, the need for adequate funding for mental health outreach and treatment programs for the elderly under the Center for Mental Health Services.

I appreciate the Committee's patience and having us present before you. Thank you.

[The information follows:]



Statement of  
Paul D. S. Kirwin, MD  
Program Director, Geriatric Psychiatry Fellowship  
Dept. of Psychiatry, Yale University School of Medicine  
New Haven, Connecticut

Representing the  
American Association for Geriatric Psychiatry  
Bethesda, Maryland

To the  
Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
U.S. House of Representatives

March 18, 2009  
2:00 PM

*Summary:*

*AAGP testimony focuses on fiscal year 2010 appropriations for mental health research and services at the Department of Health and Human Services and addresses the impending public health crisis caused by an unprecedented increase in the burden of mental disorders among older adults, especially the baby boom generation. The recommendations include:*

- *An Institute of Medicine (IOM) study to examine the access and workforce barriers unique to geriatric mental health care services. IOM is supportive of such a study and has indicated that the approximate cost would be \$1 million;*
- *The need for increased funding for Geriatric Health Professions Education Programs under Title VII of the Public Health Service Act to increase the number of geriatric specialist health care providers;*
- *An increase in funding for aging grants in the National Institute of Mental Health, National Institutes of Health;*
- *A GAO study on spending by NIH on conditions and illnesses related to the mental health of older adults. A GAO study of the work being done by the 16 NIH institutes in areas that predominately involve older adults could provide crucial insights into possible new areas of cooperative research, which in turn will lead to advances in prevention and treatment for these devastating illnesses; and*
- *Increased funding (to \$20 million) for the Mental Health Outreach and Treatment for the Elderly Program under the Center for Mental Health Services, Substance Abuse and Health Services Administration.*



**Testimony of the American Association for Geriatric Psychiatry on March 18, 2009  
Before the Appropriations Subcommittee on Labor, Health and Human Services, and  
Education**

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to testify before the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on issues related to fiscal year (FY) 2010 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by aging adults.

AAGP appreciates the work this Subcommittee has done in recent years in support of funding for research and services in the area of mental health and aging through the National Institutes of Health and the Substance Abuse and Mental Health Services Administration. Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

***A National Health Crisis: Demographic Projections and the Mental Disorders of Aging***

With the baby boom generation nearing retirement, the number of older Americans with mental disorders is certain to increase in the future. By the year 2010, there will be approximately 40 million people in the United States over the age of 65. Over 20 percent of those people will experience mental health problems. The number of ethnic and minority elders in the population is increasing as well, with the number of African American elders doubling and a tripling of the number of Latinos.

The cost of treating mental disorders can be staggering. It is estimated that total costs associated with the care of patients with Alzheimer's disease is over \$100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and crippling family burden. These psychiatric symptoms, associated with Alzheimer's disease, can increase the cost of treating these patients by more than 20 percent. However, these costs pale when compared to the costs of not treating mental disorders including lost work time, co-morbid illness, and increased nursing home utilization. It is also important to note the added burden, financial and emotional, on family caregivers, as the nation's informal caregiving system is already under tremendous strain and will require more support in the years to come.

Depression is another example of a common diagnosis among older persons. Of the approximately 32 million Americans who have attained age 65, about five million suffer from depression, resulting in increased disability, general health care utilization, and risk of suicide. Depression is associated with poorer health outcomes and higher health care costs. Those with depression are more likely to be hospitalized and experience almost twice the number of medical

visits than those without depression. Finally, the cost and number of prescriptions for this group were more than twice than those without depression.

Older adults also have the highest rate of suicide compared to any other age group. The suicide rate for those 85 and older is twice the national average. More than half of older persons who commit suicide visited their primary care physician in the prior month.

***Preparing a Workforce to meet the Mental Health Needs of the Aging Population***

In 2008, the Institute of Medicine (IOM) released a study of the readiness of the nation's healthcare workforce to meet the needs of its aging population. *The Re-tooling for an Aging America: Building the Health Care Workforce* called for immediate investments in preparing our health care system to care for older Americans and their families. Virtually all healthcare providers need to be fully prepared to manage the common medical and mental health problems of old age. In addition, the number of geriatric health specialists, including mental health providers, needs to be increased both to provide care for those older adults with the most complex issues and to train the rest of the workforce in the common medical and mental health problems of old age. The small numbers of specialists in geriatric mental health, combined with increases in life expectancy and the growing population of the nation's elderly, foretells a crisis in health care that will impact older adults and their families nationwide. Unless changes are made now, older Americans will face long waits, decreased choice, and suboptimal care. AAGP is part of the new Eldercare Workforce Alliance, a national organization of 25 organizations representing consumers, family caregivers, the direct-care workforce, and health care professionals, that has been formed to proposed practical solutions to strengthen our eldercare workforce and improve the quality of care.

In order to implement the IOM report, AAGP believes that there are several critical issues that this Committee should address:

**IOM Study on Geriatric Mental Health Workforce**

AAGP believes that the broad scope of the 2008 IOM study, while meeting a crucial need for information on the many issues regarding the health workforce for older adults, precluded the in-depth consideration of the workforce needed for treating mental illness. The study should be followed by a complementary study focused on the specific challenges in the geriatric mental health field. This study should follow up the general IOM study in two specific ways: it should examine the access and workforce barriers unique to geriatric mental healthcare services; and, in discussing possible alternative models of geriatric service delivery (such as medical homes, PACE programs, collaborative care models like those demonstrated in the IMPACT and PROSPECT studies), it should articulate the importance of integrating geriatric mental health services as intrinsic components. "The Retooling the Health Care Workforce for an Aging America Act," S. 245/H.R. 46, contains a provision mandating this additional study.

In discussions with AAGP, the senior staff of IOM suggested the following language for inclusion in the Labor/HHS Appropriations bill:

*The Committee provides \$1,000,000 for a study by the Institute of Medicine of the National Academy of Sciences to determine the multi-disciplinary mental health workforce needed to*

*serve older adults. The initiation of this study should be not later than 60 days after the date of enactment of this Act, whereby the Secretary of Health and Human Services shall enter into a contract with the Institute of Medicine to conduct a thorough analysis of the forces that shape the mental health care workforce for older adults, including education, training, modes of practice, and reimbursement.*

#### **Title VII Geriatric Health Professions Education Programs**

The Bureau of Health Professions in the HHS Health Resources and Services Administration (HRSA) administers programs aimed to help to assure adequate numbers of health care practitioners for the nation's geriatric population, especially in underserved areas.

The geriatric health professions program supports three important initiatives. The Geriatric Education Center (GEC) Program, within defined geographic areas, provides interdisciplinary training for health care professionals in assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans.

The Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Professionals (GTPD Program) provides fellows with exposure to older adult patients in various levels of wellness and functioning and from a range of socioeconomic and racial/ethnic backgrounds.

The Geriatric Academic Career Awards (GACA) support the academic career development of geriatricians in junior faculty positions who are committed to teaching geriatrics in medical schools across the country. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of health care professionals. AAGP supports increased funding for these programs as a means to increase geriatric specialist health care providers. Specifically AAGP supports:

- Expanding GECs to include at least one center in each of the 50 states and more than one in states that cover large geographic areas or have large populations;
- Expanding GEC grants to offer mini-fellowships in geriatrics to faculty members of medical schools and other health professions schools, including psychology, pharmacy, nursing, social work, dentistry, and public health;
- Enhancing GACA awards to support and retain clinician educators from a variety of disciplines as they advance in their careers; and
- Providing full funding for the National Center for Workforce Analysis to analyze current and projected needs for health care professionals and paraprofessionals in the long-term care sector.

#### ***National Institutes of Health (NIH) and National Institute of Mental Health (NIMH)***

With the graying of the population, mental disorders of aging represent a growing crisis that will require a greater investment in research to understand age-related brain disorders and to develop new approaches to prevention and treatment. AAGP would like to call to the Subcommittee's attention the fact that, even in the years in which funding was increased for NIH and the NIMH, these increases did not always translate into comparable increases in funding that specifically address problems of older adults. For instance, according to figures provided by NIMH, NIMH total aging research amounts decreased from \$106,090,000 in 2002 to \$85,164,000 in 2006

(dollars in thousands: \$106,090 in 2002, \$100,055 in 2003, \$97,418 in 2004, \$91,686 in 2005, \$85,164 in 2006).

The critical disparity between federally funded research on mental health and aging and the projected mental health needs of older adults is continuing. If the mental health research budget for older adults is not substantially increased immediately, progress to reduce mental illness among the growing elderly population will be severely compromised. While many different types of mental and behavioral disorders occur in late life, they are not an inevitable part of the aging process, and continued and expanded research holds the promise of improving the mental health and quality of life for older Americans. This trend must be immediately reversed to ensure that our next generation of elders is able to access effective treatment for mental illness. Federal funding of research must be broad-based and should include basic, translational, clinical, and health services research on mental disorders in late life.

As the NIMH utilizes the new funding from “The American Recovery and Reinvestment Act of 2009,” it is necessary that a portion of those funds be used to invest in the future evidence-based treatments for our nation’s elders. Beginning in FY 2010, annual increases of funds targeted for geriatric mental health research at NIH should be used to: (1) identify the causes of age-related brain and mental disorders to prevent mental disorders before they devastate lives; (2) speed the search for effective treatments and efficient methods of treatment delivery; and (3) improve the quality of life for older adults with mental disorders. Improving the treatment of late-life mental health problems will benefit not only the elderly, but also their children, whose lives are often profoundly affected. Caregiving itself is an enormous drain on the financial security and health of family members, many of whom become depressed or experience exacerbations of their own medical problems and disabilities.

#### Participation of Older Adults in Clinical Trials

Federal approval for most new drugs is based on research demonstrating safety and efficacy in young and middle-aged adults. These studies typically exclude people who are old, who have more than one health problem, or who take multiple medications. As the population ages, that is the very profile of many people who seek treatment. Thus, there is little available scientific information on the safety of drugs approved by the Food and Drug Administration (FDA) in substantial numbers of older adults who are likely to take those drugs. Pivotal regulatory trials never address the special efficacy and safety concerns that arise specifically in the care of the nation’s mentally ill elderly. This is a critical public health obligation of the nation’s health agencies. Just as the FDA has begun to require inclusion of children in appropriate studies, the agency should work closely with the geriatric research community, health care consumers, pharmaceutical manufacturers, and other stakeholders to develop innovative, fair mechanisms to encourage the inclusion of older adults in clinical trials. Clinical research must also include elders from diverse ethnic and cultural groups. In addition, AAGP urges that Federal funds be made available each year for support of clinical trials involving older adults.

As little emphasis has been placed on the development of new treatments for geriatric mental disorders, AAGP would encourage the NIH to promote the development of new medications specifically targeted at brain-based mental disorders of the elderly. AAGP urges this Committee to request a GAO study on spending by NIH on conditions and illnesses related to the mental

health of older individuals. The NIH has already undertaken, in its Blueprint for Neuroscience Research, an endeavor to enhance cooperative activities among NIH Institutes and Centers that support research on the nervous system. A GAO study of the work being done by these 16 institutes in areas that predominately involve older adults could provide crucial insights into possible new areas of cooperative research, which in turn will lead to advances in prevention and treatment for these devastating illnesses.

#### Development of New Investigators

Investments in the development of new investigators who initiated peer-reviewed research ensure that federal taxpayers' dollars support the growth and progress of basic and clinical neuroscience. Without the entry of new investigators, the progress of our scientific enterprise is threatened. Federal support of programs that provide incentives for young scientists to pursue careers has significantly eroded in the past decade, to the point where medical and graduate students are actively discouraged from pursuing academic research careers. To recruit and maintain a highly talented scientific investigator workforce, the Federal government must take the lead in providing incentives and support.

#### *Center for Mental Health Services*

It is critical that there be adequate funding for the mental health initiatives under the jurisdiction of the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. AAGP was pleased that the final SAMHSA budgets for the last eight years have included \$5 million for evidence-based mental health outreach and treatment to the elderly. AAGP worked with members of this Subcommittee and its Senate counterpart on this initiative, and urges an increase in funding from \$5 million to \$20 million for this essential program to disseminate and implement evidence-based practices in routine clinical settings across the states. Of that \$20 million appropriation, AAGP believes that \$10 million should be allocated to a National Evidence-Based Practices Program, which will disseminate and implement evidence-based mental health practices for older persons in usual care settings in the community. This program will provide the foundation for a longer-term national effort that will have a direct effect on the well-being and mental health of older Americans.

#### *Conclusion*

AAGP recommends:

- An IOM study on the geriatric mental health workforce to examine the access and workforce barriers unique to geriatric mental healthcare services and, to articulate the importance of integrating geriatric mental health services as intrinsic components;
- Increased funding for the geriatric health professions education programs under Title VII of the Public Health Service Act;
- A GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals.
- Increased funding for evidence-based geriatric mental health outreach and treatment programs at CMHS.

## BIOGRAPHICAL SKETCH

Name: <b>Paul D.S. Kirwin, M.D.</b>
Position: Program Director, Geriatric Psychiatry Fellowship, Department of Psychiatry, Yale University School of Medicine
Education Summary: B.A. The Colorado College, 1980 M.D. University of Rochester, 1992 Psychiatry Residency, Yale University, 1993-1996 Geriatric Psychiatry Fellowship, University of Pennsylvania, 1996-1997
Relevant Prior Experience: Legislative Correspondent/Aid, Office of Senator Gary Hart, Washington, DC, 1982-1984 Assistant Clinical Professor of Psychiatry, Yale University School of Medicine, 1997-2003 Associate Clinical Professor of Psychiatry, Yale University School of Medicine, 2003-2006 Associate Director, Geriatric Psychiatry Fellowship Program 1997-2002 Training Director, Geriatric Psychiatry Fellowship Program 2002-2006 Interim Director of Education and Training, Department of Psychiatry, VA Connecticut 2006-2007 Program Director, Department of Psychiatry, Yale University School of Medicine, 2006-2008 Director, Geriatric Psychiatry Service, West Haven VACHS 1997-2006, 2008-- Program Director, Geriatric Psychiatry Fellowship, Yale University School of Medicine, 2008-- Associate Professor of Psychiatry, Yale University School of Medicine, 2006--
Responsibilities/ Activities: Program Director, Geriatric Psychiatry Fellowship Training Program, Yale University School of Medicine Director, Geriatric Psychiatry Service, VA Connecticut Healthcare System Member, Graduate Medical Education Committee, Yale University School of Medicine Chair, Committee on Physician Health, Yale-New Haven Hospital Director, Psychosocial Curriculum, Preclinical Clerkship: Design, plan, organize and implement the clinical skills teaching in the first two years of the medical school curriculum. Director, Literature and Medicine Seminar, Bi-weekly meetings open to all medical students. 2003--Present. Separate Seminar run for Residents/Faculty. Co-Director, "Psychosocial Aspects of Illness", Pre-Clinical Clerkship for MS-1s. 2004--Present. Teach seminars in Late Life Depression, Psychosis, Dementing Illnesses, Resident as Teacher/Mentor, Clinical Skills Assessment for Psychiatry Residents
Participation in Research for the last five years: Research: Investigator, VA Central Office Health Services Evaluation Project, "Unified Psychogeriatric Biopsychosocial Evaluation and Treatment (UPBEAT)" Principal Investigator: Robert Rohrbaugh, M.D., Co-principal investigator: Laurie Harkness, Ph.D. \$693,000 over three years in direct costs, \$231,000/year. Funded 1994-1997. Renewed for \$693,000 over 3 years (1998-2001). Mentor and Co-Investigator with Jimmy Choi, Ph.D. "Efficacy of a personalized approach to rehabilitation in Alzheimer's disease", Department of Veterans Affairs, Veterans Health Administration Rehabilitation Research and Development Service Research Career Development Award (RCDA), \$420,000. 3 years (2006-2009) Education: Investigator, Integrated Model of Aging and Geriatric Education (IMAGE), The Reynolds Project at Yale School of Medicine, Director: Margaret Drickamer, M.D. Co-Directors: Richard Maritoll, M.D. and Robert Rohrbaugh, M.D.; Funded 2001-2005 for \$4,000,000

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

<p>Your Name, Business Address, and Telephone Number:</p> <p>Paul Kirwin, M.D.          Psychiatry 116A          VA Connecticut Health Care System          950 Campbell Avenue          West Haven, CT. 06516          203-932-5711, x2476</p> <p>Associate Professor of Psychiatry          Yale University School of Medicine</p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p>American Association for Geriatric Psychiatry</p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?</p> <p><input checked="" type="radio"/> Yes      No</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p> <p>Mentor and Co-Investigator with Jimmy Choi, Ph.D. "Efficacy of a personalized approach to rehabilitation in Alzheimer's disease", Department of Veterans Affairs, Veterans Health Administration Rehabilitation Research and Development Service Research Career Development Award (RCDA), \$420,000, 3 years (2006-2009)</p>

Signature: Paul B. Kwan MD Date: 02/16/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.



Mr. OBEY. Thank you very much. We appreciate your testimony. The next party on the list I am told is not here, and so we will move to Christine Lubinski, Infectious Diseases Society of America.

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WEDNESDAY, MARCH 18, 2009.

**INFECTIOUS DISEASES SOCIETY OF AMERICA**

**WITNESS**

**CHRISTINE LUBINSKI**

Ms. LUBINSKI. Good afternoon.

IDSA is pleased to testify about the urgent need to increase funding for HHS programs that address two deadly global pandemics: HIV/AIDS and tuberculosis.

IDSA and its sister organization, the HIV Medicine Association, represent more than 8,000 infectious disease and HIV physicians and scientists.

In 2008, IDSA and HIVMA launched the ID Center on Global Health Policy and Advocacy to address global HIV, TB and HIV/TB co-infection.

U.S. leadership has been a catalyzing force in saving millions of lives from HIV, but only about one-third of persons in developing countries who are clinically eligible for treatment are receiving it, and prevention strategies to reduce the more than 7,000 new HIV infections that occur daily are urgently needed.

CDC's Global AIDS Program helps poor countries prevent HIV infection, improve treatment care and support for people living with HIV and build health care capacity. An fiscal year 2010 funding level for CDC GAP of \$225,000,000 is essential to fulfill its mission as the lead agency on global HIV prevention and public health systems strengthening.

TB is the second leading global infectious disease killer, claiming more than 1.7 million lives every year.

Highly drug-resistant forms of TB have emerged. Drug-resistant TB is a direct result of human failure—failure to adequately treat TB and develop the tools necessary to address this ancient and deadly scourge. The increase in multi-drug resistant TB and the emergence of extremely drug-resistant TB raise concerns about the potential for an untreatable XDR TB epidemic.

The global spread of drug-resistant TB presents a persistent public health threat to the U.S. TB is an airborne infection. Drug-resistant TB anywhere in the world translates into drug-resistant TB everywhere.

Last year, Congress passed the Comprehensive TB Elimination Act of 2008 to enhance our capacity to address drug-resistant TB and escalate development of new tools, drugs, diagnostics and vaccines. Promises made in this law can't be fulfilled without funding. The \$210,000,000 funding level authorized in the law should be appropriated for the CDC Division of TB Elimination.

IDSA is extremely pleased that the stimulus bill contained an infusion of desperately needed dollars for NIH. This long overdue increase must be maintained and enhanced in this year's bill.

The success of HIV research is a testament to the value of research investment. A comprehensive research portfolio was responsible for the rapid and dramatic gains in HIV knowledge that led to an 80 percent reduction in AIDS mortality in the U.S. and in developing countries. Continued investment is essential to develop more effective prevention strategies and better treatment to aid prevention.

NIH funding for TB totaled \$160,000,000 in fiscal year 2008, a modest level for an infectious disease that kills millions through a pathogen that is showing increased resistance to available drugs. We must have resources for trials on new TB drugs, to test diagnostics, to evaluate vaccine candidates.

Research activities focused on HIV/TB co-infection must continue. TB is the leading cause of death among persons with AIDS, and it is more difficult to treat in people with HIV. Living with HIV and dying from TB has become an all too familiar mantra.

A doubling of funding for TB research is a reasonable response to the world disease burden and the scientific opportunities.

Finally, we support funding for the Global Fund to Fight AIDS, TB and Malaria. It provides a quarter of all international financing for AIDS globally, two-thirds for tuberculosis and three-quarters for malaria. The Global Fund has helped save 3.5 million lives in 140 countries.

Thank you very much.  
[The information follows:]

House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services,  
Education & Related Agencies Appropriations  
Public Witness Hearing  
March 18, 2009  
2:00 pm

Christine Lubinski  
Vice-President for Global Health  
Infectious Diseases Society of America  
Testimony Concerning FY 2010 Funding at the Department of Health  
and Human Services on Programs Related to Tuberculosis and  
Global HIV/AIDS at the Centers for Disease Control and Prevention,  
and the National Institutes of Health

The Infectious Diseases Society of America's (IDSA) is pleased to submit testimony about the urgent need to increase funding for the Department of Health and Human Services' programs that address two deadly global pandemics-- HIV/AIDS and tuberculosis.

IDSA represents more than 8,000 infectious diseases and HIV physicians and scientists devoted to patient care, education, research, prevention and public health. Nested within the IDSA is the HIV Medicine Association (HIVMA), representing more than 3500 physicians, scientists, nurse practitioners and other health professionals working in HIV medicine. In 2008, IDSA and HIVMA launched the Infectious Diseases Center on Global Health Policy and Advocacy to address global HIV/AIDS, tuberculosis, and HIV/TB co-infection. Under the leadership of a scientific advisory committee of world-renowned scientific experts in these areas, IDSA works to educate policymakers, U.S. government program implementers and the media about evidence-based policies and programs and the value of U.S. leadership in combating these deadly and synergistic epidemics.

#### **Global HIV/AIDS Pandemic**

There are 33 million people living with HIV/AIDS in the world, with 22 million of them or 67 percent living in sub-Saharan Africa. AIDS kills 2 million people annually. U.S. leadership has been the catalyzing force for preventing millions of infections, ensuring access to lifesaving HIV treatment for 3 million persons in developing countries, and providing care and support to millions of additional people, including orphans and vulnerable children. Despite tremendous progress, only about one-third of persons in developing countries who are clinically eligible for antiretroviral therapy are receiving it, and an ongoing and robust prevention campaign is essential to reduce the more than 7,000 new HIV infections that still occur on a daily basis.

NIH-funded HIV research at the NIH research led to the development of lifesaving antiretroviral therapy, identified the efficacy of antiretroviral therapy during pregnancy to prevent mother-to-child transmission, demonstrated the HIV prevention benefits of male circumcision, and is paving the road to the availability of an effective microbicide. The Centers for Disease Control and Prevention (CDC) have been a critical implementing partner in the US response to the global HIV epidemic, working with health ministries in developing countries to launch HIV prevention and treatment programs, conducting public health evaluation research, and supporting heavily impacted countries in their efforts to monitor and to employ evidence based strategies in response to their particular epidemics.

#### **Tuberculosis**

Tuberculosis is the second leading global infectious disease killer, claiming more than 1.7 million lives annually. Worldwide, one-third of the world's population is infected with TB and nearly 9 million people develop active TB disease each year. In recent years, highly drug-resistant forms of TB have emerged. Drug-resistant tuberculosis is a direct result of human failure-- failure to adequately detect and treat TB and to develop the necessary tools to effectively address this ancient and deadly scourge.

In 2006, the CDC and the World Health Organization reported the findings from a survey of TB reference laboratories around the world indicating that 20 percent of M. tuberculosis isolates were multi-drug resistant (MDR)—that is, TB strains resistant to the two most potent drugs in the 4-drug TB regimen. Four percent of these MDR-TB strains were resistant to multiple second-line drugs and were deemed extensively drug-resistant TB or XDR-TB. Mortality from XDR-TB can be as high as 85 percent, and close to 100 percent in individuals co-infected with HIV/AIDS. The increase in MDR-TB and the advent of XDR-TB have triggered grave alarm in the scientific community about the potential for an untreatable XDR-TB epidemic.

The global pandemic and alarming spread of drug-resistant TB present a persistent public health threat to the United States. Tuberculosis is an airborne infection. Drug-resistant TB anywhere in the world easily translates into drug-resistant TB everywhere.

#### **Deadly Synergy of HIV/TB Co-infection**

The costly MDR TB epidemic in the US in the early 1990s emerged against a background of HIV infection in high HIV prevalence cities like New York City and Miami. Today, HIV-TB co-infection is ravaging sub-Saharan Africa. TB is the leading cause of death of persons with HIV worldwide. Tuberculosis facilitates HIV disease progression, and persons with HIV have poorer TB treatment outcomes than their non-HIV-infected counterparts. It is widely expected that the World Health Organization will release new data on March 24<sup>th</sup>—World TB Day—showing much greater numbers of HIV/TB co-infected persons and higher TB mortality among HIV-infected persons than had previously been thought.

#### **CDC- Tuberculosis**

Last year, Congress passed landmark legislation—the Comprehensive Tuberculosis Elimination Act of 2008—Public Law 110-873. This bill authorizes a number of actions that will shore up state TB control programs, enhance US capacity to deal with the serious threat of drug-resistant tuberculosis and escalate our efforts to develop urgently needed new “tools” in the form of drugs, diagnostics and vaccines. Realizing these goals will require additional resources; at a minimum, it is critical that the funding authorized for FY 2010 in this important new law—\$210 million—be appropriated for the CDC Division of TB Elimination. While this represents an increase over current funding, the scientific community, including the National Coalition for the Elimination of Tuberculosis, has estimated that \$528 million will be needed annually to implement strategies through the CDC that will advance the goal of TB elimination.

Funds are desperately needed to increase the clinical trial capacity of the Tuberculosis Trials Consortium (TBTC) to evaluate promising new drugs for MDR TB and to support clinical trials for vaccine candidates that hold the hope of eliminating the scourge of TB from the face of the earth. Additional financial support is also needed for the Tuberculosis Epidemiologic Studies Consortium (TBESC) -- critical partnerships between TB control programs and academic institutions aimed at designing, conducting and evaluating programmatically relevant research.

Strengthening CDC's Division of TB Elimination to conduct research and support state TB control programs will protect our communities, and help ensure that another devastating outbreak of drug-resistant tuberculosis that plagued several American cities in the late 1980s does not recur. Ultimately, modest federal investments will prevent the necessity to expend huge resources treating MDR-TB and XDR-TB, which can cost \$468,000 per case to treat.

#### **CDC- Global AIDS Program (GAP)**

CDC's Global AIDS Program (GAP) helps resource-poor countries prevent HIV infection; improve treatment, care, and support for people living with HIV; and build health care capacity and infrastructure. To meet these objectives, CDC sends clinicians, epidemiologists and other health professionals to help foreign governments and health institutions with a range of prevention, care and support activities. Working closely with health ministries in developing countries, CDC helps build sustainable public health capacity in laboratory services and systems, including country capacity to design and implement HIV surveillance systems and surveys.

The CDC GAP also plays an important role in helping governments monitor and evaluate the impact of HIV prevention, care and treatment programs. CDC GAP also works with the Office of the Global AIDS Coordinator as the lead on HIV prevention, and also works to evaluate the impact of US HIV prevention, treatment and care and support funding. For example, CDC GAP is currently conducting a public health evaluation (PHE) to assess the impact of PEPFAR funding on developing country health systems and access to other health care services. A funding level for CDC's GAP program of at least \$218 million is essential.

#### **National Institutes of Health**

The National Institutes of Health is the world's flagship biomedical research institution, supporting basic science research, behavioral research, drug and diagnostic development and research training. Unfortunately in recent years, NIH funding has eroded, and stagnant funding has resulted in decreasing support for original research and cuts in clinical trial networks. With only one in four approved research applications receiving funding, the pipeline for critical discoveries is dwindling and young scientists are being forced to turn their attention to different professional pursuits.

IDSA is extremely pleased that the recently enacted stimulus bill contained an infusion of billions of desperately needed dollars for the NIH research enterprise. Congress rightfully acknowledged the role of scientific research in stimulating the economy. It is vital, however, that the long overdue increases in funding enjoyed by the NIH in the economic stimulus bill are maintained and enhanced in this year's funding bill—funding that will ultimately translate into improvements in individual and public health, both domestically and globally.

### **HIV/AIDS Research**

The successes of the HIV research investment is a testament to the value of research investment. A robust and comprehensive research portfolio was responsible for the rapid and dramatic gains in our HIV knowledge base, gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in developing countries where treatment has been made available. Remarkable discoveries helped us to reduce mother-to-child HIV transmission to nearly 1 percent in the U.S. and this intervention has prevented HIV infection in hundreds of thousands of children worldwide. A continued robust HIV research effort is essential to accelerate our progress in developing more effective prevention strategies, and supporting the basic research necessary to continue our work developing a vaccine that may end the deadliest pandemic in human history. Research to improve treatment strategies to aid prevention and to maximize the benefits of antiretroviral therapy, especially in underserved populations in the U.S. and in resource-limited settings is a high priority.

The National Institute on Allergies and Infectious Diseases (NIAID) is the principal funding resource for basic and clinical HIV research, but critical HIV research is conducted through a range of NIH Institutes under the leadership of the Office for AIDS Research (OAR).

### **Tuberculosis Research**

NIAID is also a critical player in tuberculosis research. In 2007, NIAID developed a research strategy for drug resistant tuberculosis, but limited resources have slowed implementation of this strategy. According to the NIH Research Portfolio Online Reporting Tool, RePORT, NIH funding for tuberculosis research, including vaccine research totaled \$160 million in fiscal year 2008—a modest level for an infectious disease that kills millions through a pathogen that is showing increasing resistance to available medications. In fact, funding for TB research has gone in the wrong direction since NIH spent \$211 million on TB research in FY 2007. A doubling of funding for TB research would be a reasonable response to the world disease burden and the current scientific opportunities.

We must increase our investment in TB research as highlighted in the enacted Comprehensive TB Elimination Act of 2008. We must have the resources to conduct clinical trials on new therapeutics for both drug-susceptible and drug-resistant TB, to test new diagnostics in point-of-care settings, and to evaluate promising TB vaccine candidates. We urgently need treatment regimens that are shorter in duration and less toxic. Research related to pediatric tuberculosis, including drug development, must be stepped up.

It is also imperative that research activities focused on HIV/TB co-infection continue with enhanced funding. Tuberculosis is the leading cause of death among persons with HIV/AIDS worldwide. TB is more difficult to diagnose in persons with HIV and a number of important anti-TB drugs interact with HIV antivirals. Critical questions remain about how best to sequence HIV and TB treatment in co-infected individuals—questions with life and death ramifications for millions of individuals, especially those living in sub-

Saharan Africa. Tuberculosis threatens to undermine the tremendous progress that has been made in saving the lives of persons in developing countries through the provision of antiretroviral therapy.

**Global Fund to Fight AIDS, Tuberculosis and Malaria**

Historically, one-third of US funding for the Global Fund has been appropriated through the NIAID budget and IDSA strongly supports a significant US contribution to the Global Fund. US support for the Global Fund to Fight AIDS, Tuberculosis and Malaria is a crucial part of US global health diplomacy. The Global Fund is a country-led, performance-based partnership that embraces transparency and accountability, and fosters multilateral cooperation. The Global Fund provides a quarter of all international financing for AIDS globally, two-thirds for tuberculosis, and three-quarters for malaria. Through these efforts, the Global Fund has helped save 3.5 million lives in 140 countries

In Pakistan, for example, an American-based international aid group called Mercy Corps has, using Global Fund resources, partnered with the private sector on a broad TB public education campaign, training thousands of health workers, and strengthening lab capacity to test for TB. This work has dramatically increased Pakistan's ability to detect TB cases, and now Pakistan is counting on the Fund's strong, continued support to ensure medication is available to people with TB. Continued progress on TB is essential to development in Pakistan, since 80% of Pakistanis afflicted with tuberculosis are in the most economically productive years of their lives, and the disease sends many self-sustaining families into poverty.

The Global Fund projects an \$8 billion need for new and continuing programs in 2010, but only \$3 billion in pledges are in place. The Labor, Health and Human Services Budget, through NIH, has been a crucial source of funding for the US contribution to the Fund, providing \$300 million in FY 2009. The Global Fund has requested that the US triple its total contribution for FY 2010. The portion of the US contribution provided by NIH should therefore be tripled to \$900 million. The economic, strategic and moral case for this contribution to the Global Fund is clear, and the US must do its part to help close this funding gap.

The IDSA and the HIVMA have many funding priorities to champion in the Labor-HHS-Education Appropriations bill including funds to address antimicrobial resistance, child and adult immunizations, pandemic influenza, the Ryan White CARE Act, and domestic HIV prevention. Thank you for the opportunity to highlight our funding priorities for research and programs related to global HIV and TB in the Labor-HHS-Education account.



**Subcommittee on Labor, HHS, Education  
& Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself / herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

Christine Lubinski  
Vice-President for Global Health  
Infectious Diseases Society of America  
1300 Wilson Boulevard, Suite 300  
Arlington, VA 22209  
703-299-5027

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

On behalf of the Infectious Diseases Society of America

2. Have you or any organization you are representing received any Federal grants or contracts (including any sub-grants or subcontracts) since October 1, 2006?

☒ Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

**HIV Medicine Assoc. of the Infectious Diseases Society of America**  
Dept of HHS, CDC – Cooperative Agreement #U65/CCU324394 9/1/2005 – 8/31/2007 awarded \$255,051

**IDSA's Emerging Infections Network:**  
Dept of HHS, CDC – Specialized Center Cooperative Agreement 1U50CI000358 7/1/2006 – 6/30/2007 awarded \$243,335  
Dept of HHS, CDC – Specialized Center Cooperative Agreement 1U50CI000358 7/1/2007 – 6/30/2008 awarded \$453,304  
Dept of HHS, CDC – Specialized Center Cooperative Agreement 1U50CI000358 7/1/2008 – 6/30/2009 awarded \$343,496

Signature,



Date: March 16, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**CHRISTINE LUBINSKI**

*Vice President of Global Health of  
the Infectious Disease Center for Global Health Policy and Advocacy*

Christine Lubinski is the Infectious Diseases Society of America's Vice President for Global Health and director of the IDSA/HIVMA's Infectious Diseases Center for Global Health Policy and Advocacy. Under the leadership of a world-renowned group of physician scientists, Ms. Lubinski and her staff focus on US policies and programs related to the global AIDS pandemic, global tuberculosis, and HIV/TB co-infection.

Ms. Lubinski was the founding executive director of the HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA), a professional organization that represents more than 3600 HIV clinicians and scientists, a position she held from 2001 until October 2008. Ms. Lubinski has more than 25 years of federal policy analysis and advocacy experience in Washington, D.C. Her primary focus is health policy.

Prior to joining IDSA in 1998, Christine Lubinski served as the deputy executive director for programs at AIDS Action Council, a national AIDS advocacy group, for more than 5 years. She was the lead policy spokesperson for AIDS Action and led federal advocacy, community outreach, and media advocacy programs. Before joining AIDS Action, she served from 1983-1993 as director for public policy at the National Council on Alcoholism and Drug Dependence focusing mainly on health care access and discrimination facing people living with a stigmatizing illness. She served as a professional staff member to the Senate Committee on Labor and Human Resources with a portfolio of public health and social service programs. She has also served as a service provider, directing programs for abused women and their children and homeless women.

Mr. OBEY. Thank you very much. We appreciate your testimony. Next, Helen Keller International, Robert Thomas, Jr.

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WEDNESDAY, MARCH 18, 2009.

**HELEN KELLER INTERNATIONAL**

**WITNESS**

**ROBERT M. THOMAS, JR.**

Mr. OBEY. Who is that strange fellow with you?

Mr. THOMAS. I think it is someone you know, actually.

Mr. OBEY. Okay.

Mr. THOMAS. Thank you very much for this opportunity for Helen Keller International and me to testify on behalf of HKI's ChildSight Program.

My name is Bob Thomas. I am a volunteer trustee of HKI. HKI was co-founded in 1915 by the deaf and blind crusader, Helen Keller, as a lead nonprofit organization dedicated to preventing the causes and consequences of blindness, poor vision and malnutrition.

I am requesting that you recommend continued funding of ChildSight through the U.S. Department of Education in fiscal year 2010.

ChildSight's mission is to improve the vision and academic potential of school children living in urban and rural poverty. Uncorrected refractive error, what most of us know more commonly as nearsightedness, farsightedness and astigmatism, two of which I have, significantly affects a child's academic performance and overall development.

ChildSight's data, collected over 15 years, confirm that up to 1 in every 4 children between the ages of 10 and 15 fail standard vision screenings. There is a simple, very cost-effective solution: prescription eyeglasses. However, millions of children in the U.S. suffer from uncorrected vision due to social, economic, transportation barriers as well as inadequate treatment under existing school health programs.

ChildSight tackles this challenge by going directly into schools with populations of children from poor families. The hallmark of the ChildSight program is the provision of prescription eyeglasses at the school.

I recently visited one of our sites in New York City. This was a middle school on the edge of Chinatown. The population there was mainly Oriental, children of Oriental extraction from various parts of the Far East, and African American children.

It was done in the school library, which was a very warm and well-used place I might note, and I am afraid it was the first time I had been in a public school for a long time.

We had volunteers there who conducted initial screenings which basically consist of reading the eye chart with the big E at the top that we are all familiar with. Anyone that showed any possible problems was then referred to one of the two optometrists that we had there that day. They were both extremely good with these children, very engaged with them, and you could see that the children

easily talked to them about what their problems were. They examined their eyes and wrote a prescription.

The child was then sent to a table where we had 30 or 40 different frames for these glasses available, and this is a key part for the children because if we can't find them something that either is acceptable or even cool they won't wear them. And they pick out the frame.

One week later, after we have sent off the prescriptions to a manufacturer, we come back and the frames, and the glasses are distributed to the kids and adjusted as necessary.

I brought a couple of pictures of the results here. One might say some of our satisfied customers.

With support from this Committee, the Department of Education and private donations, ChildSight has now screened over 1.2 million children in 7 States and has delivered free eyeglasses to 139,000 students since the program's inception in 1994.

Teachers report that a majority of the students who have their vision corrected with ChildSight glasses exhibit increased class participation and improved grades.

I ask the Committee to recognize our concern that much more needs to be done. Children who need eyeglasses must have them while they are in school, so they can make full use of their educational opportunities.

I ask the Committee to recommend at least \$1,800,000 in fiscal year 2010 to support ChildSight in its current locations and to expand our sites so that, as we say, we can bring education into focus.

Thank you, Mr. Chairman. The attention and consideration of the Committee are greatly appreciated.

[The information follows:]



352 Park Avenue South  
Suite 1200  
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212-532-0544  
212-532-6014 fax

**Statement by**

**Robert M. Thomas, Jr.**

**Treasurer and Chair, Finance Committee**

**Board of Trustees**

**Helen Keller International**

**Subcommittee on Labor, Health and Human Services,**

**Education and Related Agencies**

**Committee on Appropriations**

**U.S. House of Representatives**

**March 18, 2009, 2 p.m.**

**Robert M. Thomas, Jr., is testifying on behalf of ChildSight®, the domestic program of Helen Keller International that provides free, in-school vision screenings and prescription eyeglasses for children living in urban and rural poverty in the U.S.**

Mr. Chairman, thank you for this opportunity to appear before the Committee on behalf of Helen Keller International's ChildSight® program. My name is Bob Thomas, and I serve as the volunteer Treasurer of Helen Keller International and Chair of the Finance Committee of HKI's Board of Trustees. I am requesting that you recommend that \$1.8 million of funding through the United States Department of Education be used in support of the HKI ChildSight® program in fiscal year 2010. It is our hope that, with the continued support of the Department of Education and private donors, we can deliver vision screenings and eyeglasses to thousands of children unable to afford eye care.

### CHILDSIGHT®

ChildSight® is distinguished by its high clinical standards and its efforts to educate children and their families about the importance of corrected vision and the availability of related healthcare resources in their community. The hallmark of the program is the provision of prescription eyeglasses at the school site. As a service, it is prompt and convenient, and it seeks to overcome the economic, social and transportation barriers that prevent many poor children from obtaining the vision care they need. ChildSight® provides direct access to vision screening and refraction by a licensed optometrist, who then prescribes the necessary lenses for each child. Students who need eyeglasses receive them – on-site and free of charge – within one week.

But ChildSight® goes even one step further. Students identified with potentially severe vision problems beyond basic refractive error are referred to our partnering ophthalmologists for further evaluation and treatment (as needed), at no additional cost. This final step ensures that children who need comprehensive eye care will be able to receive it, regardless of their family's ability to pay.

With support from this Committee, the Department of Education and private donations, ChildSight® has now screened over **1.2 million** impoverished children in over 500 schools nationwide and has delivered free prescription eyeglasses to more than **139,000** students since the program's inception in 1994. The children served by ChildSight® come from families who live within 200% of the federal poverty level and have extremely limited access to basic health or vision care. All of our services are provided at no expense to the child's family.

We have seen the positive results of the ChildSight® program. Teachers we have surveyed throughout the country report that a majority of students who had their vision corrected with ChildSight® eyeglasses exhibited:

- significant improvement in the completion of schoolwork and homework;
- increased class participation and a reduction in disruptive behavior; and
- a dramatic improvement in grades, self-confidence and self-perception.

I had the opportunity to see ChildSight® in action. Recently, I visited one of our New York City sites that serves predominantly immigrant populations. I was there on the day we screened the students to test their vision and, where appropriate, our optometrists examined their eyes and prescribed corrective lenses. The children then selected frames for their new eyeglasses from the wide variety we make available. The process was a model of efficient organization and warm

engagement with the children. In many children, one could already see the anticipation of receiving their eyeglasses in a few days.

### CHILDREN WITH VISUAL NEEDS

The mission of ChildSight® is to improve the vision and academic potential of schoolchildren living in urban and rural poverty. Vision and learning are inextricably linked. Most learning platforms – books, computer screens, blackboards, overhead projectors, and classroom presentations – require clear vision in order for a child to interact, assimilate information, and respond. Uncorrected refractive error (more commonly known as near-sightedness, far-sightedness and astigmatism) can significantly affect a child's academic performance and overall development.

Our data, collected over 15 years of service, confirms that one in every four children between the ages of 10 and 15 fail standard vision screenings as a result of refractive error.

Children with undetected or uncorrected vision problems are at a major disadvantage in school and may be unfairly perceived as learning disabled, low achieving, or anti-social. Among poor, predominantly minority, public school students throughout our nation, the inability to learn due to poor vision is widespread, and largely unaddressed. Millions of children in the U.S. suffer from uncorrected refractive error due to various social, economic and transportation barriers, as well as inconsistent or inadequate treatment under existing school health programs.

Poor vision materially and adversely affects a child's *quality* of life, often resulting in lost education and future employment opportunities, lower productivity, emotional frustration, and social exclusion.

The good news is that refractive error, which is one of the most common treatable health conditions of childhood, has a simple, cost-effective solution: the provision of correctly prescribed eyeglasses.

ChildSight® tackles this challenge by going directly into the schools to conduct vision screenings, to identify children with refractive error, and to provide them with prescription eyeglasses to correct this error, all free of charge. By supplying students with an essential learning tool – eyeglasses – ChildSight® helps to ensure these children can take advantage of all the educational opportunities available to them.

### AREAS SERVED BY CHILDSIGHT®

Helen Keller International established ChildSight® in New York City in 1994. Today the program serves children in over 30 urban and rural communities in seven states: California (Los Angeles), Connecticut (Bridgeport, Hartford, New Haven and New London), New Jersey (Newark, Irvington, Jersey City, Orange, East Orange, Passaic and Plainfield), New Mexico (Gallup), New York (New York City), Ohio (Cleveland and East Cleveland) and Texas (El Paso).

Support from the Department of Education has played a key role in the success and growth of the program. The rapid geographic expansion achieved from 2000 to 2005 would not have been possible without the support of the Department of Education.

Department of Education support was particularly instrumental in the establishment of ChildSight®'s rural programs serving isolated communities surrounding El Paso, Texas, and Gallup, New Mexico. For example, in Gallup, recognizing the enormous burden of rural poverty, the severe lack of health resources and the barriers to accessing care, Helen Keller International established ChildSight® in Gallup-McKinley County, New Mexico. Since then, ChildSight® New Mexico has screened over 16,000 children throughout the county, including critically underserved children living on the Navajo Reservation, and has provided over 4,000 children with the prescription eyeglasses they needed to focus and thrive in the classroom.

### **PROGRAM INNOVATION**

HKI's ChildSight® also continually seeks to improve and expand its program through innovation. One such program innovation is the ChildSight® Pre-K vision screening program, which was launched in New York City in 2005. Modeled after the original ChildSight® program, which targets children between ages 10 and 15, ChildSight® Pre-K addresses the unmet vision care needs of low-income children between ages 3 and 4, the age range when amblyopia (also known as "lazy eye") can be strategically identified and treated. Since 2005, ChildSight® Pre-K has now provided sight-saving services to over 10,500 pre-school children throughout New York City, most of whom had never received any eye health services before.

### **PUBLIC/PRIVATE UNDERTAKING**

ChildSight® is truly a public/private endeavor. The program's success is due in large part to the dedication and commitment of the many physicians, educators, community activists and business people at each of our local sites. Along with their support and the generous contributions of foundations and corporations, we continue to seek the institutionalization and long-term sustainability of our programs. Previous endorsement and support by the Department of Education have played an important role in our ability to leverage committed support from the private sector. ChildSight® has received significant long-term funding from several foundations including the Annenberg Foundation, the Community Foundation for Greater New Haven, the Eisner Foundation, the Lavelle Fund for the Blind, the Reader's Digest Partners for Sight Foundation, the Rose Hills Foundation, the Starr Foundation, and the William Knox Holt Foundation.

Local health care professionals at each of our sites are members of the ChildSight® team, and more than 40 optometrists and pediatric ophthalmologists help us meet the vision care needs of the students we serve. ChildSight® contracts with 21 ophthalmic clinics and seven optical shops nationwide, all selected for their strong professional credentials. Services of all these community professionals are either donated or provided at a reduced, reasonable rate.

### **SOLVING THE PROBLEM**

I ask that the Committee recognize our concern that so much more needs to be done. Children who need eyeglasses must receive them while they are still in school, so that they can make full use of their educational opportunities. I also ask you to consider the reality that children in many areas of urban and rural poverty are missing the chance to be helped because we cannot yet reach them. If students must struggle with the blurred, imprecise images they see on textbook pages, on the blackboard and in classroom demonstrations, then their opportunity to gain an

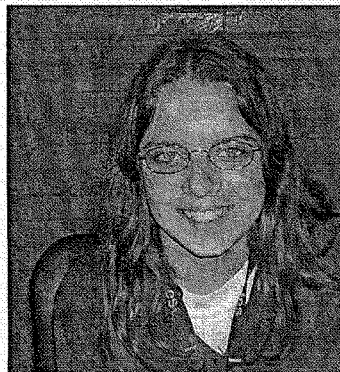
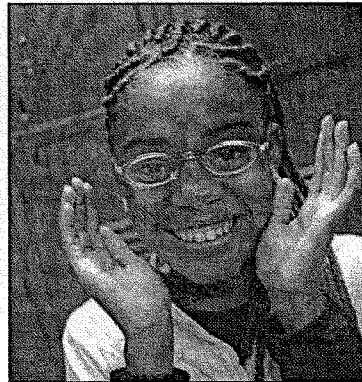
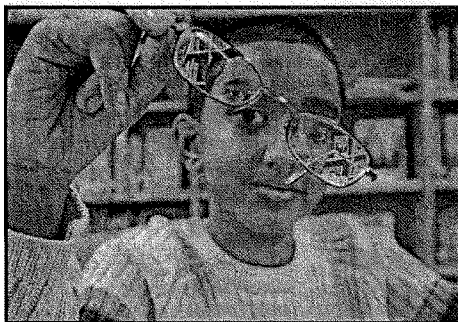


adequate education in our public schools is being wasted. This is especially tragic since this is a result of an easily fixable but neglected visual deficiency.

**If we receive the \$1.8 million of requested funding, it will support our ongoing programs, and it will enable us to screen the vision of approximately 125,000 additional children during the 2010-2011 school year.** ChildSight® is needed now more than ever as many families are faced with unemployment, reduced wages, unaffordable health insurance, elusive credit, and other financial constraints stemming from the current economic downturn. For a family struggling to pay for basics such as food, housing and utilities, a trip to the eye doctor or a pair of prescription eyeglasses is simply unaffordable, leaving many low-income children with uncorrected vision problems – and lost opportunities.

In closing, I ask the committee to recommend at least \$1.8 million dollars in fiscal year 2010 to support ChildSight® in its current locations, to expand the current sites, and to explore its potential expansion in other regions of the country.

Thank you, Mr. Chairman. Your attention and consideration are greatly appreciated, and I close with the wise words of our founding board member, Helen Keller: *If we look at difficulties bravely, they will present themselves to us as opportunities.*”



**ROBERT M. THOMAS, JR. – TREASURER AND CHAIR, FINANCE COMMITTEE**

Mr. Thomas joined Sullivan & Cromwell LLP in 1969 after graduating from the University of Kansas (BA, 1962) and Harvard Law School (LL.B, 1966). He served as a partner of the firm from 1975 through 2007, was the Managing Partner of the London Office 1979-1982 and of the Beijing Office 2005-2007, and held the position of Managing Partner of the General Practice Group from 1984 through 1991. He currently is “Of Counsel.”

He joined the HKI Board of Trustees in 2003 and resides in New York City. He is a Trustee of the University of Kansas Endowment, a director of the Sheffield (Massachusetts) Land Trust and serves on the Manhattan Council of the Boy Scouts of America in New York City.



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#### **RULE XI STATEMENT**

In accordance with Rule XI of the Rules of the House of Representatives, Helen Keller International states that its witness has not received any Federal grant or contract during the current fiscal year or either of the two previous fiscal years. The entity represented by the witness, Helen Keller International, has received grants totaling approximately \$14,000,000 - \$15,000,000 during the current fiscal year, \$11,016,090 during fiscal year 2008 and \$ 7,843,353 during fiscal year 2007. The grants were related to programs for blindness prevention, nutrition, and eye care.

Helen Keller International's ChildSight® program has received Federal grants (or sub-grants thereof) from the following in fiscal year 2008. No funds have yet been awarded in fiscal year 2009.

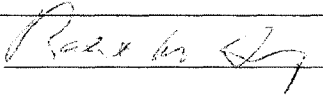
- U.S. Department of Education, Fund for the Improvement of Education: \$1,196,722 awarded to Helen Keller International's ChildSight® program in July 2008.
- U.S. Department of Education, Fund for the Improvement of Education: \$47,162 awarded specifically to Helen Keller International's ChildSight® New Mexico program in August 2008.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

<p>Your Name, Business Address, and Telephone Number:</p> <p>Robert Thomas Sullivan &amp; Cromwell LLP 125 Broad Street New York, NY 10004 212-558-3704</p>
<p>1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.</p> <p>Yes, Helen Keller International (NGO)</p>
<p>2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?</p> <p><input checked="" type="radio"/> Yes      <input type="radio"/> No</p>
<p>3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.</p> <p>See Attachment</p>

Signature:  Date: March 18, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

## Helen Keller International- Government Funding

July 1, 2007 to June 30, 2008

<u>Direct Funded - USAID</u>	<u>FY08 Funding</u>
USAID - Nutrition Vit. A - Cambodia	(\$5,332.03)
Project child Vision-Eyehealth	(\$5,131.32)
USAID-Nutrition-EnRICH-Philippines	(\$2,415.03)
USAID-Eyehealth-Indonesia-OVC	(\$5.08)
USAID-Nutrition-Mali-Comm Dev.	\$43,835.41
USAID - Nutrition - Child Survival - Niger	\$438,235.33
USAID - Nutrition - Child Survival - Mali	\$347,429.64
USAID - IT/Nutrition- West Africa	\$272,434.11
USAID / OFDA - Nutrition - Niger	(\$8,694.05)
USAID - Ed & Rehab - OVC II - Indonesia	\$1,261,295.53
USAID/OFDA - Nutrition - Burkina, Mali, Niger, ARO	\$1,190,150.51
USAID - ARMM - Philippines (HKL-Core)	\$2,867,584.47
USAID - Nutrition (SUMMIT II) - Indonesia	\$20,618.30
USAID - Nutrition (Cooking Oil) - WA (BF,Mal, Cd, Niger,Sen)	\$405,795.16
<b>TOTAL</b>	<b>\$6,825,800.95</b>
<u>Pass-Through Funded</u>	
CFSI-CRS, Niger	(\$3,239.80)
CWS-Nutrition-Indonesia-SEP	(\$548.38)
ABT-Nutrition-Mali	\$77,217.75
Save the Children (US)- Nutrition-Bangladesh	\$678,959.95
CRS-Nutrition-Senegal	\$21,496.37
PLAN-Nutrition-Child Survival -Cameroon	\$126,122.23
Chemonics - Nutrition - Mozambique	\$37,791.10
ABT-Nutrition-Senegal	\$56,413.49
CORE - Nutrition - Mali (workshop)	(\$2,507.16)
CRS - Nutrition/HIV - Senegal (Dakar and Casamance)	\$50,633.54
IMA - Nutrition - DR Congo	\$150,127.19
AWARE Engender Health - Nutrition - Senegal	\$219,669.72
CRS - MYAP - Niger	\$130,029.48
RTI - NTD (Integrated NTD Control Program)	\$1,291,946.60
3200 - AED - A2Z Nutrition	\$1,356,176.66
<b>TOTAL</b>	<b>\$4,190,288.74</b>
<b>TOTAL U.S. Government Funding</b>	<b>\$11,016,089.69</b>

July 1, 2006 to June 30, 2007

<u>Direct Funded- USAID</u>	<u>FY07 Funding</u>
Nutrition/Eyecare - Cambodia	(\$1,451.57)
Vitamin A Project	(\$2,829.50)
Nutritional Surv - Bangladesh	(\$500.23)
Project Child Vision - Eyehealth	\$332,948.03
Bridge - Nutrition - Morocco	(\$52.11)

USAID - Nutrition - EnRICH - Philippines	\$154,690.60
USAID - Eyehealth - Indonesia - OVC	(\$2,663.40)
USAID - Nutrition - Mali-Comm. Dev.	\$55,745.31
USAID - Nutrition - Child Survival - Niger	\$244,224.34
USAID - Nutrition - Child Survival - Mali	\$359,513.42
USAID - IT/Nutrition - West Africa	\$207,853.07
USIAD / OFDA - Nutrition - Niger	\$637,238.75
USAID - Nutrition Vit. A - Cambodia	\$347,835.41
USAID - Education & Rehabilitation - OVC II	\$1,306,375.55
USAID/OFDA - Nutrition - Burkina, Mali, Niger, ARO	\$369,788.80
USAID - ARMM - Philippines (HKI-Core)	\$1,040,989.66
USAID - Nutrition (SUMMIT II) - Indonesia	\$158,392.40
USAID - Nutrition (Cooking Oil) - WA (BF,Mali, Cd, Senegal)	\$75,512.03
<b>TOTAL</b>	<b>\$5,283,610.56</b>
<b>USAID Pass-Through Funded</b>	
MOST	(\$7,965.45)
CFSI-CRS, Niger	\$211,831.39
CWS - Indonesia	\$35,692.54
ABT - Mali	\$53,370.25
Chemonics - Madagascar	(\$656.37)
LEAD - MSH Philippines	(\$3,495.92)
Save the Children - Bangladesh	\$561,803.28
CRS - Nutrition/Bangladesh	\$56,207.29
PLAN - Cameroon	\$65,340.53
Chemonics - Mozambique	\$49,083.72
ABT-Nutrition-Senegal	\$25,350.82
CORIE - Nutrition - Mali (workshop)	\$17,256.47
CRS - Nutrition/HIV - Senegal (Dakar and Casamance)	\$11,940.90
IMA - Nutrition - DR Congo	\$35,161.08
AWARE Engender Health - Nutrition - Senegal	\$6,045.03
CRS - MYAP - Niger	\$105,700.63
AED - AZZ Nutrition	\$1,337,076.73
<b>TOTAL USAID Subagreements</b>	<b>\$2,559,742.92</b>
<b>Government Funding Summary</b>	
<b>US Government</b>	
USAID	\$7,843,353.48
New York City Department of Ed	\$49,367.80
	<b>\$7,892,721.28</b>
<b>July 1, 2005 to June 30, 2006</b>	
<b>Direct Funded- USAID</b>	<b>\$4,177,997.93</b>
<b>USAID Pass-Through Funded</b>	
MOST	\$2,697,059.82
CFSI	\$326.67
CFSI	\$339,852.68

CWS	\$467,665.35
ABT	\$62,632.13
CORE	\$33,903.73
JHSPH	\$722.43
Chemonics	\$13,993.24
LEAD	\$121,671.16
Save the Children	\$85,694.33
	<b>\$3,823,521.54</b>
<b>US Department of Education</b>	<b>\$223,625.00</b>
<b>Total Government Funding</b>	<b>\$8,225,144.47</b>

<b>July 1, 2004 to June 30, 2005</b>	
<u>Direct Funded- USAID</u>	<b>\$4,177,472.75</b>
<u>USAID Pass-Through Funded</u>	
MOST	\$1,053,207.11
CFSI	\$152,007.20
CWS	\$40,836.50
ABT	\$64,621.99
Chemonics	\$15,913.35
LEAD	\$234,902.11
Save the Children	\$444,198.81
CRS	\$11,096.86
PLAN	\$19,092.88
Chemonics	\$3,315.57
AED A2Z	\$316,555.83
	<b>\$2,355,748.21</b>
<b>US Department of Education</b>	<b>\$991,988.00</b>
<b>Total Government Funding</b>	<b>\$7,525,208.96</b>

Mr. OBEY. Thank you. We appreciate your testimony.  
 Next, National Association of State Alcohol and Drug Abuse Directors, Flo Stein.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL ASSOCIATION OF STATE ALCOHOL AND  
 DRUG ABUSE DIRECTORS, INC.**

**WITNESS**

**FLO STEIN**

Ms. STEIN. Chairman Obey, Ranking Member Tiahrt, members of the Committee, I am Flo Stein. I am the President of the National Association of State Alcohol and Drug Abuse Directors. We call it NASADAD. The members of NASADAD manage the publicly-funded addiction services in all of the States and territories.

I serve as the Director of Substance Abuse in the State of North Carolina, and I want to thank you very much for offering us this opportunity to provide testimony. We are very grateful for this Committee's leadership in providing funding for the States' addiction and treatment and prevention systems.

I have submitted a more detailed report that you can look at. It shows some of the issues going on in particular States and some of the outcomes those States are having.

For today, I am going to focus on three important points regarding our top priority, and that is an increase in the Substance Abuse and Prevention Block Grant of \$150,000,000. That program currently receives \$1,780,000,000.

It is a very large block grant, but I think it is important to remember that it is the foundation of the Nation's treatment system. The block grant represents half of all the dollars available in my State, for instance. In the State of Wisconsin, it represents about 48 percent of all the dollars spent.

The other primary source of financing for the public addiction, prevention, treatment and recovery system is State appropriations. So it is sort of like very limited streams of funding that come to the addiction treatment system.

A second point that I think is really important that I think we might finally be successful is that we are getting outstanding results. We have partnered with the Substance Abuse and Mental Health Services Administration on the National Outcome Measures.

The States are showing very much improved outcomes for people gaining recovery. For example, in 2008, all the States together, 63 percent of the people who received treatment were abstinent from illicit drugs, having come in being drug users and leaving treatment and recovery, and 7 percent abstinent from alcohol use.

The third point is one that you are hearing about quite a bit, and that is that the system, because it is so dependent on this important block grant, is very much under stress right now. We have increasing numbers of people needing services as the economy declines. Unfortunately, more and more people cope with the stress of their situation by sometimes using alcohol and other drugs. And,



as you have heard, alcohol and drug abuse contribute to all the leading causes of death: the chronic illnesses, heart disease, stroke and cancer.

So it is an important investment.

That is the backdrop to the request that we are asking for \$150,000,000 increase in the block grant.

The block grant has been stable for a number of years. We are very grateful to this Committee for the additional \$19,900,000 this past year. It is going to make a big difference. But because the block grant had been level funded for a number of years since 2004, we are not quite back to the original purchasing power that we had.

So I think it is an important investment in the future of our Country.

Again, thank you for your leadership, and we stand ready to answer any questions or provide additional information.

[The information follows:]



**National Association of State Alcohol and Drug Abuse Directors, Inc.**

*President*  
Flo Stein  
North Carolina

*First Vice President*  
Joe M. Hill  
Arkansas

*Vice President  
for Internal Affairs*  
J. Kent Hunt  
Alabama

*Vice President  
for Treatment*  
Emilio Vela, Jr.  
Washington

*Vice President  
for Prevention*  
Debbie Synhorst  
Iowa

*Immediate  
Past President*  
Barbara Cimaglio  
Vermont

*President NDJIC*  
Denise Colston  
Florida

*Secretary*  
Michael Botticelli  
Massachusetts

*Treasurer*  
Karen M. Carpenter-Palumbo  
New York

*Regional Directors*

Michael Botticelli, MA

*Region I*

Karen M. Carpenter-Palumbo, NY

*Region II*

TBA

*Region III*

Donna Hillman, KY

*Region IV*

Theodora Binion-Taylor, IL

*Region V*

Terri L. White, OK

*Region VI*

David Dickinson, KS

*Region VII*

JoAnne Hoesel, ND

*Region VIII*

Renee Zito, CA

*Region IX*

Andy Gadzinski, ID

*Region X*

*Interim Executive Director*  
Robert L.L. Morrison

**Testimony on FY 2010 Federal Funding for Addiction Treatment,  
Prevention, Recovery Services and Research**

**Submitted to the House Appropriations Subcommittee on Labor, Health and  
Human Services (HHS), Education and Related Agencies**

**The Hon. David Obey (WI), Chairman  
The Hon. Todd Tiahrt (KS), Ranking Member**

**Submitted by Flo Stein, Chief of Community Policy Management,  
North Carolina's Division of Mental Health, Developmental disabilities, and  
Substance Abuse Services**

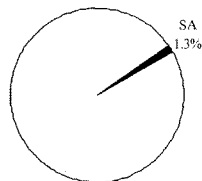
**On behalf of the National Association of State  
Alcohol and Drug Abuse Directors (NASADAD)**

**Wednesday, March 18, 2009, 2:00 p.m.**

**Regarding FY 2010 appropriations for:**

Substance Abuse and Mental Health Services Administration (SAMHSA), with a  
focus on the Substance Abuse Prevention and Treatment Block Grant;  
Department of Education's Safe and Drug Free Schools and Communities  
(SDFSC)—State grant program; National Institute on Drug Abuse (NIDA), and  
National Institute on Alcohol Abuse and Alcoholism (NIAAA).

**Substance Abuse Expenditures:  
Represented 1% of All Health Spending in 2003**



**All Health = \$1,614 billion  
Substance Abuse (SA) = \$21 billion**

SA = Substance Abuse Expenditures

National Expenditures for Mental Health Services and Substance Abuse Treatment: 1993-2003,  
T. Mark, et al. Substance Abuse and Mental Health Services Administration (SAMHSA), 2007

Chairman Obey, Ranking Member Tiahrt, members of the Subcommittee, on behalf of the National Association of State Alcohol and Drug Abuse Directors (NASADAD), and our component organizations, the National Prevention Network (NPN), and the National Treatment Network (NTN), thank you for your leadership on issues related to addiction. I am Flo Stein, NASADAD President and member from North Carolina. I am pleased to present testimony regarding FY 2010 funding priorities.

**Scope of the Problem:** According to the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Survey on Drug Use and Health (NSDUH), approximately 23.2 million Americans aged 12 or older needed services for an alcohol or illicit drug problem in 2007. During the same year, approximately 2.4 million received treatment for such a problem at a specialty facility. As a result, approximately 20.8 million people needed but did not receive services in 2007 in a specialty facility.

**Substance Abuse Spending Represents a Tiny Fraction of All Health Expenditures:** Substance abuse expenditures represented 1.3 percent of all healthcare expenditures in 2003 (\$21 billion for substance abuse compared to \$1,614 billion for all health expenditures). Using inflation adjusted terms, the growth rate for all health spending from 1993 to 2003 was 4.6 percent, while the growth rate for substance abuse spending during this same time period was 1.4 percent.

**Yet Addiction is Associated with Many Other Diseases:** In a 2004 study appearing in the Journal of the American Medical Association (JAMA), researchers examined "actual causes of death" defined by the Centers for Disease Control and Prevention (CDC) as factors that contribute to leading killers such as heart disease, cancer and stroke. The study identified nine leading "actual causes of death." Tobacco, alcohol and illicit drugs – killing 530,000 Americans in 2000 – were three of the top nine. The others were diet/weight; microbial agents; toxic agents; motor vehicles; firearms and sexual behaviors.

**Unaddressed Substance Abuse Problems are Costly:** As noted in SAMHSA's *National Expenditures for Mental Health Services and Substance Abuse Treatment, 1993-2003* (2007), when substance abuse spending was \$15.5 billion in 1998, the total economic costs of alcohol abuse were approximately \$184.6 billion and the total economic costs for drug abuse were \$143.4 billion (Harwood, 2000). These costs were linked not only to medical consequences of alcohol/drug use, but also crime, lost earnings, motor vehicle crashes, and more.

**Financial Investments in Addiction Services Save Taxpayer Dollars:** The National Institute on Drug Abuse (NIDA) notes that for every dollar spent on addiction treatment programs, there is an estimated \$4 to \$7 reduction in the cost of drug related crimes. With some outpatient programs, total savings can exceed costs by a ratio of 12:1 (NIDA InfoFacts, 2006).

**Maintain SAMHSA as Strong Agency:** NASADAD supports action to ensure that SAMHSA remains a unique, strong and vibrant agency. SAMHSA has demonstrated excellent leadership and collaboration – promoting innovative strategies to improve our service delivery system. NASADAD thanks Dr. Eric Broderick, Acting Administrator of SAMHSA, for his work. SAMHSA is to be commended and should be considered a vital voice in discussions related to health reform.

**o Priority for FY 2010 – Increase Funding for Substance Abuse Prevention and Treatment**

**(PT) Block Grant:** NASADAD recommends \$1,928.6 million for the SAPT Block Grant in FY 2010 – an increase of \$150 million over FY 2009. Since 2007, as the economy and State budgets struggled, unemployment grew by 5.5 million. This is critical news for the SAPT Block Grant given that the NSDUH found unemployed persons need services at almost twice the rate as those with jobs.

increase in SAPT Block Grant funds would help our public treatment system to better serve this increased need on the part of the low income and uninsured population.

*Background:* The SAPT Block Grant, a program distributed by formula to all States and territories, serves our nation's most vulnerable, low income populations: those with HIV/AIDS, pregnant and parenting women, youth, and others. This vital program helps States and communities address their own unique needs – whether the problem is alcohol, methamphetamine, and prescription drug abuse or persons using multiples substances. The SAPT Block Grant represents approximately 40 percent of treatment expenditures by State substance abuse agencies across the country.

*SAPT Block Grant Funded Services Achieve Results:* The SAPT Block Grant is an effective and efficient program that emphasizes accountability through the reporting of outcomes data. In particular, States have worked diligently with SAMHSA to implement the National Outcome Measures (NOMs) initiative. The SAMHSA/State partnership on NOMs promotes continuous quality improvement through a more systematic approach to data management and reporting. States now measure the impact of services on the use of alcohol and other drug use; employment; having stable housing; involvement with criminal activity; and efforts to live productively in the community. As noted by SAMHSA in 2008, SAPT Block Grant funded programs had positive results, where "...at discharge, clients have demonstrated high abstinence rates from both illegal drug (68.3 percent) and alcohol (73.7 percent) use."

In my own State of North Carolina, our Division of Mental Health, Developmental Disabilities and Substance Abuse Services reported 21,102 to treatment admissions in State Fiscal Year 2006/2007. In the Fiscal Year 2006/2007, North Carolina showed the following client outcomes at discharge: 82 percent were abstinent from alcohol use; 74 percent were abstinent from drug use; and 77 percent were involved in social support groups.

*Important Prevention Funding within SAPT Block Grant:* Twenty percent of the SAPT Block Grant is dedicated to funding much needed substance abuse prevention programming. In many States set-aside funding represents a large source of prevention funds for the agency. Overall, SAPT Block Grant funding represents 64 percent of State substance abuse agency prevention funding. In 21 States, the set-aside represents 75 percent or more of the agency's prevention budget.

The prevention set-aside has also helped produce demonstrable results. The Monitoring the Future (MTF) Survey found a 25 percent decline in any illicit drug use in the past month by 8<sup>th</sup>, 10<sup>th</sup> and 12<sup>th</sup> graders combined between 2001 and 2008. As a result, there were 840,000 fewer teens using drugs in 2008 compared to 2001. A strong commitment to the SAPT Block Grant will ensure a strong commitment to much needed prevention services for our youth.

*Recent History of SAPT Block Grant Funding:* NASADAD is thankful for the increase of \$19.9 million for the SAPT Block Grant in FY 2009. However, the program has suffered over the past few years: from FY 2004 to FY 2008, funding was cut by more than \$20 million. In fact, it is estimated that the 2010 SAPT Block Grant appropriation would have to be increased by \$403.7 million above the 2009 appropriation to maintain services at 2004 levels using the CPI-U as the proxy [Data courtesy of the New York State Office of Alcoholism and Substance Abuse Services (OASAS)]. As a result, NASADAD and others view an increase of \$150 million as a down payment to make up for lost ground.

**Center for Substance Abuse Treatment (CSAT):** NASADAD recommends \$489.3 million in FY 2010 – an increase of \$75million compared to FY 2009.

NASADAD is thankful for an increase of \$14.5 million for CSAT in FY 2009. This increase reversed the previous Administration's proposal to cut CSAT by \$63 million. The FY 2009 omnibus bill restored all or a portion of a number of NASADAD priority programs that were set to be eliminated, including:

Pregnant and Postpartum Women (\$11.8 million); Program Coordination and Evaluation, which includes Recovery Month (5.2 million); Strengthening Treatment Access & Retention (\$3.6 million); the Children and Families line – which includes the National Center on Substance Abuse and Child Welfare (NCSACW) and the State Adolescent Treatment Coordination Grant (SAC) (\$24.2 million). Other NASADAD programs that would have been significantly reduced under the previous Administration's proposed budget – yet were restored through the FY 2009 omnibus were:

Opioid Treatment Programs/Regulatory Activities (proposed cut of \$2.8 million); Targeted Capacity Expansion [TCE] (proposed cut of \$11.1 million); and the Addiction Technology Transfer Centers [ATTCs] (proposed cut of \$478,000).

NASADAD acknowledges Dr. H. Westley Clark, Director of CSAT, for his excellent leadership.

**Center for Substance Abuse Prevention (CSAP):** NASADAD recommends \$276.3 million – an increase of \$75 million compared to FY 2009.

NASADAD appreciates the \$6.8 million increase for CSAP in FY 2009. Approving the FY 2009 omnibus package restored funding for the following CSAP programs which were slated to be eliminated or reduced by the previous Administration:

Strategic Prevention Framework State Incentive Grant (a proposed cut of \$9.3 million); the Sober Truth on Prevention Underage Drinking [STOP Act] (proposed to be eliminated); Methamphetamine Prevention (proposed cut of \$2.4 million); and the Program Coordination/Data Coordination and Consolidation Center (proposed cut of \$5.2 million).

NASADAD applauds the work of Fran Harding, Director of CSAP, for her work and dedication.

**Safe and Drug Free Schools and Communities – State Grants:** NASADAD recommends \$346.5 million, representing a \$51.8 million increase over FY 2009.

The SDFSC State Grants program is an effective program that represents a core component of each State's prevention system. A number of Governors designate NASADAD members to manage these funds to ensure a more comprehensive, coordinated and effective approach to service delivery.

**National Institute on Drug Abuse (NIDA):** NASADAD is pleased with the \$25.5 million increase in FY 2009. NASADAD will support the percentage increase for NIH programs to be outlined soon by the Ad Hoc Coalition for Medical Research. NASADAD wishes to thank Dr. Nora Volkow, Director of NIDA, for her collaboration with State substance abuse agencies through its "Blending Initiative." This work improves the translation of research into everyday practice.

**National Institute on Alcohol Abuse and Alcoholism (NIAAA):** NASADAD applauds the \$14.7 million increase for NIAAA in FY 2009. NASADAD will support the percentage increase for NIH programs to be outlined soon by the Ad Hoc Coalition for Medical Research.

**Outcomes from Substance Abuse Prevention and Treatment (SAPT) Block Grant for Selected States Represented on the House Appropriations Subcommittee on Labor, HHS, Education**

*Wisconsin's Division of Disability, Elder Services, Substance Abuse and Mental Health* reported 33,314 admissions to treatment in State Fiscal Year 2007 and noted the following outcomes in 2007 for those clients completing treatment: 73 percent were abstinent at discharge; 58 percent were employed full time at discharge; 95 percent had no criminal justice activity at discharge. For prevention, the Division reported that fewer students experimented with alcohol before age 13 (37 percent in 2003 vs. 24 percent in 2005/2006) and past month marijuana use decreased (22 percent in 2003 vs. 16 percent in 2005).

*Kansas Addiction and Prevention Services Division within the Department of Social & Rehabilitation Services* reported 15,980 admissions in State Fiscal Year 2008 and noted the following outcomes comparing admission to discharge: a 64.4 percent increase in abstinence from alcohol use; a 64.2 percent increase in abstinence from drug use; a 16.5 percent increase in employment; and a 4 percent decrease in homelessness. The Division served 227,180 persons with prevention services and noted the following outcomes cited by the Kansas Communities that Care Survey: decrease in past 30 days use of alcohol (31.3% in 2006 vs. 27.2 in 2008); cigarettes (12.1 % vs. 10.4%) and marijuana (8.6% vs. 7.8%).

*Oklahoma's Department of Mental Health and Substance Abuse Services* reported 19,113 admissions to treatment and provided prevention services to 259,387 individuals in State Fiscal Year 2007. For SFY '07, the following client outcomes were reported at discharge for those completing long term residential treatment: 82 percent of clients were abstinent from alcohol; 61 percent of clients were abstinent from drugs; 36 percent of clients were employed/in school; 89 percent of clients gained or remained in stable living situations; and 91 percent of clients remained free of criminal justice involvement.

*New York's Office of Alcoholism and Substance Abuse Services (OASAS)* reports over 92,574 annual new admissions to the OASAS funded treatment system and, in the 2009 SAPT Block Grant application, included patient outcomes comparing admission to treatment to discharge: 53 percent increase in the number of patients abstinent from drug use; 28.6 percent increase in the number patients employed; 42.1 percent decrease in the number of patients who were homeless; and 51.4 percent decrease in the number of patients arrested in the past month.

*California's Department of Alcohol and Drug Programs (ADP)* reported 172,290 admissions during State Fiscal Year 2006/2007, noting the following outcomes comparing admission and discharge: 91.1 percent of clients were abstinent from alcohol use; 73.1 percent of clients were abstinent from drug use; 65 percent of clients were employed; 95.9 percent of clients reported no criminal justice involvement.

*Rhode Island's Division of Behavioral Healthcare Services* reported 8,170 admissions to treatment in 2006 and reported the following client outcomes: an 84.3 percent increase in the number of patients abstinent from alcohol; a 74.8 percent increase in the number of patients abstinent from other drugs; an 81.3 percent decrease in the number of patients arrested; and a 23 percent decrease in homelessness.

*Virginia's Department of Mental Health, Mental Retardation and Substance Abuse Services* reported 114 admissions to treatment and provided prevention services for 11,712 people in State Fiscal Year 7. For State Fiscal Year 2006, the following client outcomes were reported: approximately 50 percent of clients reported abstinence from alcohol use; 70 percent of clients reported abstinence from drug use; and approximately 40 percent of clients were employed at discharge.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Florence Stein, Chief, Community Policy Management  
North Carolina Division of Mental Health, Developmental Disabilities and Substance  
Abuse Services  
325 North Salisbury Street  
Raleigh, NC 27603  
Ph: (919) 733-4670

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

North Carolina Department of Health and Human Services  
Division of Mental Health, Developmental Disabilities and Substance Abuse Services

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

<u>Grant Name</u>	<u>Grant Amount</u>
NC Strategic Prevention Framework State Incentive Grant	\$2,332,000
Substance Abuse Prevention and Treatment Block Grant	\$38,487,034
Social Services Block Grant	\$8,685,464
Mental Health Block Grant	\$10,962,898
Safe and Drug Free Schools and Communities Program	\$1,322,046
Enforcing Underage Drinking Laws Block Grant Program	\$700,000
New Freedom Initiative Financial Support - Olmstead	\$20,000
TBI Implementation Grant	\$100,000
PATH - Projects in the Transition for Homelessness	\$914,000
NC Adolescent Treatment Coordination Project	\$400,000
Comprehensive Automated Uniform System Enhancement	\$142,200
Prescription Drug Monitoring	\$399,900
State Outcomes Measurement and Management System (SOMMS)	\$150,000
DASIS	\$96,765
<b>Total</b>	<b>\$64,712,307</b>



Signature: *Jo Stein* Date: *March 18, 2009*

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.



Mr. OBEY. Thank you.

Ms. LEE. Mr. Chairman, may I just ask one quick question, please?

Mr. OBEY. Sure.

Ms. LEE. Thank you very much.

Let me ask you, and I know this would entail a longer discussion, but I want to ask you about the treatment approaches and funding now for prescription drug use as it relates to recovery versus the illicit drug use. How is that working at this point?

Ms. STEIN. I can specifically for my State, but we have also had a number of discussions with the States that are members of NASADAD. This is our fastest growing problem both for children and adults but more alarmingly for children.

What we are doing is just refocusing our dollars. We have the same number of dollars, and we are trying to develop new intervention techniques and especially working with families because the source of a lot of prescription drugs is actually people's homes. So we want parents to be more aware and be watching their children.

We would be glad to send you some further ideas about what can be done.

Mr. OBEY. Thank you. Thank you very much.

Let me tell the Committee that I am told that between 3:00 and 3:30 we will have the next series of votes. That means that we will be gone for 30 to 40 minutes. So, if we get lucky and that vote comes closer to 3:30 than 3:00, we might be able to finish all of our witnesses before we have to leave them in the lurch.

Let me next call upon the Association of Maternal and Child Health Programs, Phyllis Sloyer.

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WEDNESDAY, MARCH 18, 2009.

## **ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS**

### **WITNESS**

**PHYLLIS SLOYER, PH.D., R.N.**

Ms. SLOYER. Good afternoon, Mr. Chairman and Subcommittee Members. I am grateful for the opportunity to testify on behalf of the Association of Maternal and Child Health Programs, its members and the millions of women and children that we serve through the Title V Maternal and Child Health Services Block Grant every year.

I am Dr. Phyllis Sloyer. I am the current President of AMCHP, and I am also a division director in the State of Florida.

I am here today to respectfully ask the Subcommittee to support full funding for the Maternal and Child Health Services Block Grant at its authorized level of \$850,000,000, and I want to begin with Adam's story.

Adam is a 15-year-old from Milwaukee, Wisconsin, a cute guy. I am going to paraphrase in his words the benefits that he has received from this Title V block grant.

He says: Hi. My name is Adam, and I live in Milwaukee, Wisconsin. I have a very rare genetic disorder that affects my ability

to see, to learn and to move, and Title V services have been very important to me.

His mother says: It is great to see that more services are becoming available through the funding, especially the five regional centers in the State of Wisconsin. These centers are dedicated to meeting family needs through information referral, follow-up services, parent-to-parent support and the building of a tremendous network of providers who help children with special health care needs.

He wants you to know that families with kids who have special needs really do benefit from these services, and he wants us to help him so that other kids can get the services as well.

He says, thanks.

Now we know that two of these centers are actually in Chairman Obey's district. One is at the Chippewa County Courthouse, and the other one is at the Marathon County Health Department, and they are not unusual. We have used Title V funds throughout the Nation to develop similar centers and similar networks to help children like Adam.

But I would like to point out a few high points about Title V and Title V of the Social Security Act. It was created during the Great Depression. It is a unique Federal-State partnership that is dedicated solely to improving the health of all mothers and children including children with special health care needs.

I can't begin to tell you the millions of people that have received early prenatal care, child health screening, preventative services, support services because of this block grant. I also can't begin to tell you the kinds of systems of services that we have developed because of these funds.

While we have made great strides in preventing long-term problems, the data are indicating now that we need to bolster our actions. Every 18 minutes, a baby dies before his or her first birthday. Basically, a dozen of them will die before the end of my testimony.

Globally, we are 29th in infant mortality. We are failing to adequately screen all young children for developmental issues. I think you all know about the obesity problems and the health disparity problems. And only 50 percent of children with special health care needs actually receive comprehensive care through a medical home.

Third, we have a proven track record of measuring what we do, and that data are fairly transparent, but it is beginning to tell us that we have a demand for services that is going beyond our capacity.

Our States are facing significant economic challenges. Frankly, every day, I have a ten-fold increase in the number of people that are coming to us for services, whether they are prenatal care, whether they are preventative services, whether they are screening services.

Our block grant is at its lowest funding level of \$662,000,000 since 1993. We need the additional resources not for us but for the women and children who come to us. I urge you to consider full funding at \$850,000,000.

And I close with the story of Ashley in my State, whose mother had to make a decision between getting the eyeglasses her daughter needed to stay in school or the drugs that her daughter needed

to be in a regular classroom. Through the efforts of Title V and coordinating with other agencies, she is in a regular classroom, and she is grateful that she is as a teenager.

For all the Adams and Ashleys and the millions served by this remarkable block grant, thank you for the opportunity to share our story and thank you for your leadership.

[The information follows:]



**Statement from Phyllis Sloyer, R.N., Ph.D., PAHM, FAAP**

**President, Association of Maternal and Child Health Programs  
(AMCHP)**

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202-775-0436  
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Presented to the:

**House of Representatives Committee on Appropriations  
Subcommittee on Labor, Health and Human Services and Education**

March 18, 2009

**Summary: To improve the health of all women, infants, children, and adolescents, including children with special health care needs, the Association of Maternal and Child Health Programs (AMCHP) is asking for the subcommittee's leadership to appropriate \$850 million for the Title V Maternal and Child Health Services Block Grant administered by the Health Resources and Services Administration of the U.S. Department of Health and Human Services.**

Mr. Chairman and distinguished Subcommittee Members:

I am grateful for this opportunity to testify on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women and children that are served by the Title V Maternal and Child Health Services Block Grant. My name is Dr. Phyllis Sloyer and I am the current President of AMCHP as well a division director at the Florida Department of Health. I am here today to ask the Subcommittee to support full funding for the Title V Maternal and Child Health Services Block Grant at its authorized level of \$850 million for Federal Fiscal Year 2010.

To help illustrate the importance of Title V MCH Funding, I want to begin by sharing the story of a boy named Adam, in his own words:

*Hi! My name is Adam and I live in Milwaukee, WI. I have a very rare genetic disorder that affects my vision, cognitive abilities, and motor skills. Title V services have been very important to my family. It's great to see more services are becoming available through the funding, especially the five Wisconsin Regional Centers for Children and Youth with Special Health Care Needs. These centers are dedicated to meeting families' needs through a statewide coordinated system of information, referral and follow up, family to family support, and strong partnerships with providers. I want you to know that families that have kids with special needs really do benefit from the services offered through Title V. Please help so that other kids like me can develop to their best potential through access to these services. Thanks!*

While Adam lives in Milwaukee, we know that the Title V MCH Block Grant in Wisconsin supports two regional centers in Chairman Obey's district. The Western Regional Center for Children and Youth with Special Health Care Needs (CYSHCN) is located at the Chippewa County Courthouse and the Northern Regional Center is located in the Marathon County Health Department. The MCH Block Grant supports a similar network in my home state of Florida, and none of this could happen without the Title V MCH Block Grant funding.

Title V of the Social Security Act was created during the Great Depression to "improve the health of all women and children." The MCH Block Grant is a celebrated example of an effective Federal and state partnership with a common goal of improving the health of all mothers and children, including those children with special health care needs. It is also at the forefront of promoting family-centered care in all of its work. But we are losing ground fast and we believe it is time to go back to the roots of Title V and recommit ourselves to truly improving the health of our nation's women and children by fully investing in the MCH Block Grant.

Despite major advances in medicine, technology, and our health care system, America still faces huge challenges to improving maternal and child health outcomes and addressing the needs of very vulnerable children.

Reductions in maternal and infant mortality have stalled in recent years and rates of preterm and low birth weight births have increased over the last decade. As we sit here today, the United States ranks 29<sup>th</sup> in infant mortality rates when compared to other nations. Every 18 minutes a baby in America dies before his or her first birthday. Each day in America we lose 12 babies due to a Sudden, Unexpected Infant Death. There are places in this country where the African American infant mortality rate is double, and in some places even triple, the rate for whites. Childhood obesity threatens to reverse a century of progress in extending life expectancy, preventable injuries remain the leading cause of death for all children and we are failing to adequately screen all young children for developmental concerns.

Sadly, there are gaps between what a family needs and actually receives for a child with a special need. Out of pocket health care costs are increasing and we are erasing gains we made in supporting effective services for children with special needs and their families. Only 50% of these children receive comprehensive care within the context of a medical home and less than 20% of youth with special needs are able to find an adult health care provider who can appropriately care for them.

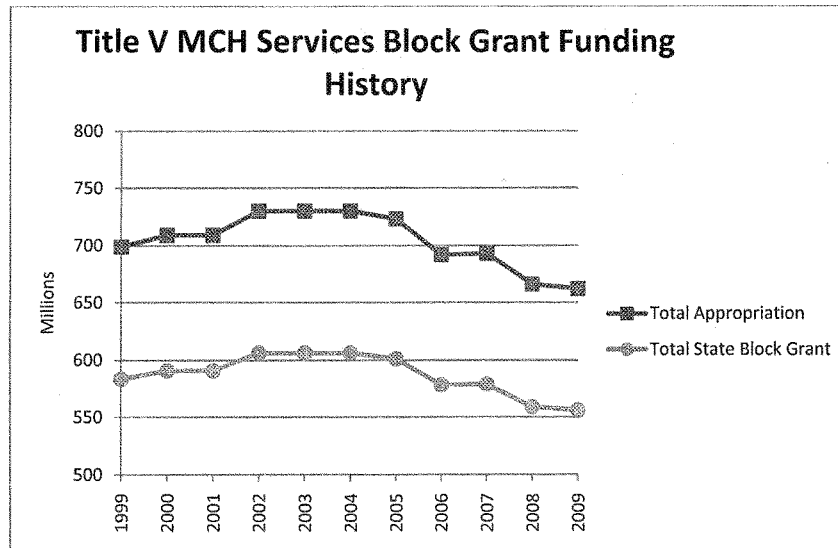
State programs funded through MCH Block Grant dollars are key to reversing this picture. Considering these and many other urgent health needs, AMCHP asks for your leadership in fully funding the MCH Block Grant at \$850 million for FY 2010.

AMCHP urges Congress to recognize the need to revitalize resources for states and their partners to reverse the trends and continue this critical work. We have a track record of demonstrating that we make a positive difference and are fully accountable for the funds that we receive. Fully funding the MCH Block Grant is an effective and efficient way to invest in our nation's women, children, and families.

The Office of Management and Budget found that MCH Block Grant-funded programs deliver results and decrease the infant mortality rate, prevent disabling conditions, increase the number of children immunized, increase access to care for uninsured children, and improve the overall health of mothers and children. Close coordination with other health programs assures that funding is maximized and services are not duplicated.

Our results are available to the public through a national website known as the Title V Information System. Such a system is remarkably rare for a federal program and we are proud of the progress we have made.

Despite the increasing demand for maternal and child health services, reductions to the MCH Block Grant threaten the ability of programs to carry out their work. As states face increasing economic hardship, more women and children will seek services through MCH Block Grant funded programs. Due to years of reduced investment, the MCH Block Grant is at its lowest funding level since 1993, \$662 million dollars, meaning states again are being asked to serve additional people with less.



Now, as economic troubles increase demand for health services, state MCH programs desperately need additional resources to:

- increase outreach and screening services to identify and link women and children to available health care services;
- assure coordination of those services and assist new parents through efforts such as expanded home visitation programs; and
- deliver essential prevention and health promotion services to make sure that every mom has a healthy pregnancy; every child has the opportunity for a healthy birth and strong start in life; and every child with special health care needs receives ongoing comprehensive care within a medical home.

Crucial MCH activities are also supported by Title V under the Special Projects of Regional and National Significance (SPRANS) program, including MCH research, training, hemophilia diagnostic and treatment centers, and MCH improvement projects that develop and support a broad range of strategies. The SPRANS investment drives innovation for MCH programs and is an important part of the Title V MCH Block Grant.

Mr. Chairman and distinguished members, in closing I ask you to imagine with me an America in which every child in the United States has the opportunity to live until his or her first birthday; a nation where our Federal and state partnership has effectively moved the needle on our most pressing maternal and child health issues. Imagine a day when we are celebrating significant reductions or even the total elimination of health disparities by creatively solving our most urgent maternal and child health challenges. The MCH

Block Grant aims to do just that – using resources effectively to improve the health of all of America’s women and children.

I want to close with one more story from a parent in my state that I think illustrates the personal impact of Title V MCH Block Grant funds:

*My daughter Ashley continues to be at risk for a detached retina with myopia of the eye. Title V Children and Youth with Special Health Care Needs has been instrumental in providing medically necessary funding for the type of eyeglasses that she needs in order to be able to see and have some quality of life as an adolescent. There are medications that she needs to be able to control her executive functions, her impulses and her motor coordination in order to be able to function in school that I would not be able to afford as a parent. As a parent it would be devastating if she could not go to school which increases her chances of being able to transition into work and/or higher education.*

Thank you.



**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Phyllis Stoyer  
2030 M Street NW  
Washington DC 20036 202 775-0436

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

on behalf of the Association of  
Maternal & Child Health Programs  
(non-gov)

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes ☐ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

provided in e-mail

Signature: Phyllis Stoyer Date: 3/18/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you very much.  
 Now, Health Professions and Nursing Education Coalition, Dr. Tina Cheng.

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WEDNESDAY, MARCH 18, 2009.

**HEALTH PROFESSIONS AND NURSING EDUCATION  
 COALITION**

**WITNESS**

**DR. TINA L. CHENG, M.D.**

Dr. CHENG. Good afternoon. My name is Tina Cheng, and I am Chief of the Division of General Pediatrics and Adolescent Medicine and Professor of Pediatrics and Public Health at Johns Hopkins University up the road, and it is a pleasure to speak to you today on behalf of the Health Professions and Nursing Education Coalition or HPNEC in support of \$550,000,000 in fiscal year 2010 for the health professions education programs authorized under Title VII and VIII of the Public Health Service Act and administered through HRSA.

HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals and students dedicating to ensuring the health care workforce is trained to meet the needs of our diverse population.

As you know, the Title VII and VIII health professions and nursing programs are essential components of the Nation's health care safety net, bringing health care services to our under-served communities. These programs support the training and education of health care providers to enhance the supply, diversity and distribution of the health care workforce, picking up where traditional market forces leave off. In particular, the programs emphasize primary care and training in interdisciplinary settings to meet the needs of special and under-served populations.

We are thankful to the Subcommittee for the \$200,000,000 provided for the health professions programs in the American Recovery and Reinvestment Act. We also greatly appreciated the recently enacted fiscal year 2009 Omnibus Appropriations Bill provides increases for most Title VII and VIII programs.

The Nation is indebted to you, Mr. Chairman, as well as members of the Subcommittee for your forward-thinking vision.

We cannot achieve universal access to health care and quality care unless we ensure that a well-prepared health care workforce is in place to provide that care. Today, however, we remain a long way from realizing that vision.

According to HRSA, an additional 30,000 health practitioners are needed to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care and a growing chronically ill and aging population, these needs strain an already fragile health care system.

In my own experience at Johns Hopkins, in collaboration with the University of Maryland Family Medicine Program, Title VII dollars have allowed us to train clinician educators and researchers

who are the primary care faculty across the Country. We have a commitment and a strong track record of training under-represented minorities and, in the last two decades, have trained almost 100 pediatric and family medicine trainees, 61 percent of them, under-represented minorities, most all serving under-served populations today and most doing research on health disparities.

As noted while I was on HRSA's Advisory Committee on Training in Primary Care Medicine and Dentistry, the education and training of our health care providers is an integral part in preparing our Country to meet the health needs of the future as well as current and growing health needs, many that you have heard about already today: mental health, global health issues, et cetera.

Because of the time required to train health professionals, we must make appropriate investments today. HPNEC's \$550,000,000 recommendation for Title VII and Title VIII health professions programs will help sustain the health care workforce expansion supported by funding in the recovery package. Further, this appropriation will restore funding to critical programs that still have not recovered from the substantial funding lost in the drastic fiscal year 2006 cuts.

We are grateful to President Obama for his support of the health professions program throughout his tenure in the Senate. We also appreciate the pledge in his fiscal year 2010 budget to invest in strengthening the health professions workforce.

We look forward to working with the Subcommittee to help achieve this goal and to reinvest in the health professions program.

[The information follows:]



*Testimony of the*  
**Health Professions and Nursing Education Coalition (HPNEC)**  
**concerning Title VII & VIII Health Professions Programs**

*before the*

**House Appropriations Subcommittee on Labor,  
 Health and Human Services, and Education**

*presented*

**March 18, 2009, at 2 p.m.**

*by*

**Tina L. Cheng, M.D., M.P.H.**  
**Chief, General Pediatrics & Adolescent Medicine**  
**Professor of Pediatrics & Public Health**  
**Johns Hopkins University School of Medicine**  
**Bloomberg School of Public Health**  
**Baltimore, Maryland**  
**President, Academic Pediatric Association**

**Summary:**

- The health professions education programs, authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration, support the training and education of health care providers to enhance the **supply, diversity, and distribution of the health care workforce**, filling the gaps in the supply of health professionals not met by traditional market forces. They are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.
- According to HRSA, **an additional 30,000 health practitioners are needed** to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial/ethnic disparities in health care, and a growing, aging population, these needs strain an already fragile health care system.
- Numerous recent, highly regarded publications recommend increased support for the health professions programs to help meet these needs, including a December 2008 Institute of Medicine (IOM) report which characterized HRSA's health professions programs as **"an undervalued asset."**
- HPNEC recommends **\$550 million in FY 2010 for the Title VII and VIII programs**. This investment is consistent with President Obama's pledge to invest in strengthening the health professions workforce in the FY 2010 budget, will help sustain the health workforce expansion supported by the American Recovery and Reinvestment Act, and will restore funding to critical programs that sustained drastic funding reductions in FY 2006 and remain well below FY 2005 levels.

Good afternoon. My name is Tina Cheng, and I am Chief of the Division of General Pediatrics and Adolescent Medicine and Professor of Pediatrics and Public Health at the Johns Hopkins University School of Medicine and Bloomberg School of Public Health. It is a pleasure to submit this testimony on behalf of the Health Professions and Nursing Education Coalition (HPNEC) in support of **\$550 million in fiscal year (FY) 2010 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA).**

HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and students dedicated to ensuring the health care workforce is trained to meet the needs of our diverse population.

As you know, the Title VII and VIII health professions and nursing programs are essential components of the nation's health care safety net, bringing health care services to our underserved communities. These programs support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and VIII programs are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

We are thankful to the Subcommittee for the \$200 million provided for the health professions programs in the American Recovery and Reinvestment Act (P.L. 111-5). We also greatly appreciate that the recently enacted FY 2009 Omnibus Appropriations bill (P.L. 111-8) provides some increases for most Title VII and VIII programs. These investments provide a crucial springboard to begin to wholly reverse chronic underfunding of these programs and address existing and looming shortages of health professionals.

According to HRSA, an additional 30,000 health practitioners are needed to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial/ethnic disparities in health care, and a growing, aging population, these needs strain an already fragile health care system. Because of the time required to train health professionals, we must make appropriate investments today. Yet, despite some increases in recent years, many of the health professions programs remain well below their comparable FY 2005 funding levels.

HPNEC's \$550 million recommendation for the Title VII and Title VIII health professions programs in FY 2010 will help sustain the health workforce expansion supported by funding in the recovery package. Further, this appropriation will restore funding to critical programs that sustained drastic funding reductions in FY 2006 and remain well below FY 2005 levels.

We are grateful to President Obama for his support for the health professions programs throughout his tenure in the Senate. We also appreciate the pledge in his FY 2010 budget overview to invest in strengthening the health professions workforce. This strategy is in line with

numerous recent, highly regarded recommendations. In a December 2008 Institute of Medicine (IOM) report, HRSA's health professions programs were characterized as "an undervalued asset" and the Department of Health and Human Services was encouraged to support additional investments in the programs. Another IOM report on the future workforce for older Americans from April 2008 also called for increased funding for the health professions programs. The November 2008 issue of the peer-reviewed journal *Academic Medicine* chronicles the effectiveness of the programs, and the primary care programs in particular, while the December 2008 issue of the *Mt. Sinai Journal of Medicine* highlights the impact of the diversity programs.

These most recent publications showcase the network of Title VII and VIII initiatives across the country supporting the education and training of the full range of health providers. Together, the programs work in concert with other programs at the Department of Health and Human Services – including the National Health Service Corps and Community Health Centers (CHCs) – to strengthen the health safety net for rural and medically underserved communities.

The Health Professions Education Partnerships Act of 1998 (P.L. 105-392) consolidated the programs into seven general categories:

- The purpose of the **Minority and Disadvantaged Health Professionals Training** programs is to improve health care access in underserved areas and the representation of minority and disadvantaged health care providers in the health professions. *Minority Centers of Excellence* support programs that seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The *Health Careers Opportunity Program* seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The *Faculty Loan Repayment and Faculty Fellowship* programs provide incentives for schools to recruit underrepresented minority faculty. The *Scholarships for Disadvantaged Students (SDS)* make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students. Nurses received \$15.1 million in FY 2007 from SDS grants, 32 percent of funds appropriated for SDS.
- The **Primary Care Medicine and Dentistry** programs, including *General Pediatrics*, *General Internal Medicine*, *Family Medicine*, *General Dentistry*, *Pediatric Dentistry*, and *Physician Assistants*, provide for the education and training of primary care physicians, dentists, and physician assistants to improve access and quality of health care in underserved areas. Two-thirds of all Americans interact with a primary care provider every year. Approximately one half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not trained through these programs. The *General Pediatrics*, *General Internal Medicine*, and *Family Medicine* programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. The *General Dentistry* and *Pediatric Dentistry* programs provide grants to dental schools and hospitals to create or expand primary care dental residency training programs. Recognizing that all primary care is not only provided by

physicians, the primary care cluster also provides grants for *Physician Assistant* programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. Additionally, these programs enhance the efforts of osteopathic medical schools to continue to emphasize primary care medicine, health promotion, and disease prevention, and the practice of ambulatory medicine in community-based settings.

- Because much of the nation's health care is delivered in areas far removed from health professions schools, the **Interdisciplinary, Community-Based Linkages** cluster provides support for community-based training of various health professionals. These programs are designed to provide greater flexibility in training and to encourage collaboration between two or more disciplines. These training programs also serve to encourage health professionals to return to such settings after completing their training. The *Area Health Education Centers (AHECs)* provide clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs, which have substantial state and local matching funds, form networks of health-related institutions to provide education services to students, faculty and practitioners. *Geriatric Health Professions* programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, which are all designed to bolster the number and quality of health care providers caring for our older generations. Given America's burgeoning aging population, there is a need for specialized training in the diagnosis, treatment, and prevention of disease and other health concerns of the elderly. The *Quentin N. Burdick Program for Rural Health Interdisciplinary Training* places an emphasis on long-term collaboration between academic institutions, rural health care agencies and providers to improve the recruitment and retention of health professionals in rural areas. This program has received no funding since FY 2006. The *Allied Health Project Grants* program represents the only federal effort aimed at supporting new and innovative education programs designed to reduce shortages of allied health professionals and create opportunities in medically underserved and minority areas. Health professions schools use this funding to help establish or expand allied health training programs. The need to address the critical shortage of certain allied health professionals has been acknowledged repeatedly. For example, this shortage has received special attention given past bioterrorism events and efforts to prepare for possible future attacks. The *Graduate Psychology Education Program* provides grants to doctoral, internship and postdoctoral programs in support of interdisciplinary training of psychology students with other health professionals for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families), especially in rural and urban communities.
- The **Health Professions Workforce Information and Analysis** program provides grants to institutions to collect and analyze data on the health professions workforce to advise future decision-making on the direction of health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed a number of valuable, policy-relevant studies on the distribution and training of health professionals, including the Eighth National Sample Survey of Registered Nurses (NSSRN), the nation's most extensive and comprehensive source of statistics on registered nurses. However, the Workforce Information and Analysis program has received no appropriation since FY 2006.

- The **Public Health Workforce Development** programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The *Public Health Traineeships and Public Health Training Centers* seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. *Preventive Medicine Residencies*, which receive minimal funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. *Dental Public Health Residency* programs are vital to the nation's dental public health infrastructure. The *Health Administration Traineeships and Special Projects* grants are the only federal funding provided to train the managers of our health care system, with a special emphasis on those who serve in underserved areas. However, the traineeships have received no appropriation since FY 2006.
- The **Nursing Workforce Development** programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. These programs provide the largest source of federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support to 51,657 nursing students and nurses in FY 2008. Health care entities across the nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and capacity limitations within the educational system. Each year, nursing schools turn away between 50,000 and 88,000 qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. At the same time, the need for nursing services and licensed, registered nurses is expected to increase significantly over the next 20 years. Congress responded to this dire national need by passing the *Nurse Reinvestment Act* (P.L. 107-205) in 2002, which increases nursing education, retention, and recruitment. The *Advanced Education Nursing* program awards grants to train a variety of advanced practice nurses, including nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. For example, this funding has been instrumental in doubling nurse anesthesia graduates in the last eight years. However, even though the number of graduates doubled, the vacancy rate for nurse anesthetists has remained the same at 12 percent, due to a retiring nursing profession and an aging population requiring more care. *Workforce Diversity* grants support opportunities for nursing education for disadvantaged students through scholarships, stipends, and retention activities. *Nurse Education, Practice, and Retention* grants are awarded to help schools of nursing, academic health centers, nurse managed health centers, state and local governments, and other health care facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The *Loan Repayment and Scholarship Program* repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds. In return these students are required to work for at least two years of practice in a designated nursing shortage area. The *Comprehensive Geriatric Education* grants are used to train RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, train faculty members, and provide continuing education. The *Nurse Faculty Loan* program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty.



- The loan programs under **Student Financial Assistance** support needy and disadvantaged medical and nursing school students in covering the costs of their education. The *Nursing Student Loan* (NSL) program provides loans to undergraduate and graduate nursing students with a preference for those with the greatest financial need. The *Primary Care Loan* (PCL) program provides loans covering the cost of attendance in return for dedicated service in primary care. The *Health Professional Student Loan* (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The NSL, PCL, and HPSL programs are funded out of each institution's revolving fund and do not receive federal appropriations. The *Loans for Disadvantaged Students* (LDS) program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

These programs work collectively to fulfill their unique, three-pronged mission of improving the supply, diversity, and distribution of the health professions workforce. Profiles of aspiring and practicing health professionals who attribute their success in part to participation in the health professions programs are available by state and by program at: <http://www.aamc.org/advocacy/hpniec/profiles.htm>. These profiles comprise only a small sampling of the health professionals that have benefited from past support for the health professions programs.

HPNEC members respectfully urge support for funding of at least **\$550 million** for the Title VII and VIII programs, an investment essential not only to the development and training of tomorrow's health care professionals but also to our nation's efforts to provide needed health care services to underserved and minority communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of Congress and the new Administration to reinvest in the health professions programs in FY 2010 and into the future.

Program Director/Principal Investigator (Last, First, Middle):

**BIOGRAPHICAL SKETCH**

NAME Tina L Cheng, MD, MPH		POSITION TITLE Chief, General Pediatrics & Adolescent Medicine Professor, Johns Hopkins University School of Medicine and Bloomberg School of Public Health	
eRA COMMONS USER NAME (credential, e.g., agency login) Tcheng2			
EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)			
INSTITUTION AND LOCATION	DEGREE (if applicable)	YEAR(s)	FIELD OF STUDY
Brown University	BA, MD	1979-1986	Biology, Medicine
University of California, San Francisco & San Francisco General Hospital, CA		1986-1990	Pediatrics Residency and Chief Residency
University of California, Berkeley, CA	MPH	1990-1991	Epidemiology
University of California, Berkeley, CA		1990-1993	Preventive Medicine Residency
University of Massachusetts Medical Center, Worcester, MA		1991-1993	General Academic Pediatrics Fellowship

**A. POSITIONS and HONORS****Professional and Academic Appointments:**

- 1993-2002 Associate Professor with tenure, George Washington University (GWU)  
Department of Pediatrics, Children's National Medical Center (CNMC)  
Department of Prevention & Community Health, GWU School of Public Health  
Director of Community-Based Research, Children's Research Institute, CNMC
- 1995-present Founder and Past Director, CNMC Generations Program, Comprehensive Program for Teen  
Parents and their Children, currently Executive Board Member.
- 2002-present Chief, Division of General Pediatrics & Adolescent Medicine
- 2002-2008 Associate Professor, Department of Pediatrics, JHU School of Medicine and Public Health
- 2008-present Professor, Department of Pediatrics, JHU, Department of Population, Family & Reproductive  
Health, Bloomberg School of Public Health

**Other Experience and Professional Memberships:**American Academy of Pediatrics (AAP)

- 1989-92 Co-founder, Secretary & Chair of Resident Section, Member of Council on Ped Education
- 1996-2000 Future of Pediatric Education II, Workgroup on Education of the Pediatrician
- 1996- Associate Editor (2005-), Associate Editor In Brief (1996-2005), **Pediatrics in Review**
- 2008- Committee on Pediatric Research

Academic Pediatric Association (APA, formerly Ambulatory Pediatric Association)

- 1996-98 National Nominating Committee, elected
- 1996-99 Region IV Co-Chairperson, elected
- 2001-04 Executive Board, Chair of Membership and Regions, elected
- 2004-07 Co-Chair, Division Directors in General Pediatrics Special Interest Group
- 2006-07 Conference Convener, 1<sup>st</sup> National Leadership Conference in Academic General Pediatrics
- 2007-10 President-Elect, President, Past President, elected

Advisory Committees, Review Groups

- 1999- Agency for Health Care Policy and Research, NIH/NICHD, Maternal and Child Health Bureau  
(MCHB), Health Resources Services Administration (HRSA) Research Review Panels
- 2003 MCHB Expert Panel on Maternal and Child Health Critical Research Issues
- 2003-07 HRSA Advisory Committee on Training in Primary Care Medicine and Dentistry

**Honors and Awards**

- 1996-2000 Robert Wood Johnson Generalist Faculty Scholar
- 2000, 2001, 2003, 2005 Community Service Awards to Generations Program (founded by Cheng)
- 2008 Johns Hopkins Institutions Diversity Leadership Award

**B. SELECTED PEER-REVIEWED PUBLICATIONS of >80**

1. Cheng TL, Haynie D, Brenner RA, Wright JL, Chung SE, Simons-Morton B. Effectiveness of a Mentor-

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Tina L. Cheng, MD, MPH  
Johns Hopkins University  
200 N. Wolfe Street, Suite 2055  
Baltimore, MD 21287  
410 614 3862

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Health Professions and Nursing Education Coalition

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

X Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing:

CHENG:

10/07 - 10/12

National Children's Study Center, Wave I Center  
HHSN267200700048C  
National Institutes of Child Health and Human Development  
Total Direct Costs: \$10,826,032  
PI: Lynn Goldman  
Cheng Role: Co-Investigator; 2.5-10%

9/07 - 8/12

Enhancing Youth Violence Prevention in Urban Communities  
Mid-Career Award in Patient-Oriented Research  
1K24HD052559-01A2  
National Institutes of Child Health and Human Development

Total Direct Costs: \$791,565  
 PI: Tina Cheng  
 Role: Principal Investigator; 40-50%

- 9/07 - 5/12 DC-Baltimore Research Center on Child Health Disparities  
 2P20MD000198-06  
 NIH, National Center for Minority Health and Health Disparities  
 Total Direct Costs: \$6,133,201  
 PI: Renee Jenkins, Howard University  
 Cheng Role: JHU Site Principal Investigator; 15%
- 9/05 – 8/10 Enhanced Healthy Generations Program  
 1APHPA006026-01-00  
 Department of Health and Human Services, Office of Adolescent  
 Pregnancy Programs  
 Total Direct Costs: \$1,732,574  
 PI: Lee Beers, Children's National Medical Center  
 Cheng Role: Investigator; 11%
- 9/05 – 9/10 Center to Prevent Youth Violence, Engaging Parents in Violence  
 Prevention  
 U49CE000728  
 Centers for Disease Control and Prevention  
 Total Direct Costs: \$3,519,055  
 PI: Phillip Leaf  
 Cheng Role: Investigator & Project Principal Investigator; 5%
- 2008-09 Conference Grant: Starting Early: A Life Course Perspective on  
 Child Health Disparities: Developing a Research Action Agenda,  
 held 11/6-7/08  
 PI: Renee Jenkins, Howard University  
 National Institutes of Health (NICHD & NCMHD) \$50,000  
 Agency for Health Care Research & Quality \$10,000  
 Cheng Role: Investigator
- Cheng Previous:  
 9/02-7/07 DC-Baltimore Center to Improve Child Health Disparities  
 1 P20 MD00165-01  
 National Center on Minority Health and Health Disparities  
 Total Direct Costs: \$858,223  
 PI: Jill Joseph  
 Cheng Role: JHU Site Principal Investigator; 15%
- 9/02 – 9/07 Violence Prevention Among High-Risk Early-Adolescent Youth  
 N01-HD-2-3344  
 National Institute of Child Health and Human Development  
 Total Direct Costs: \$1,617,041  
 PI: Tina Cheng  
 Cheng Role: Principal Investigator; 0% during extension

Signature: Anna Z. Cheng Date: 3/18/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you very much.  
 Next, American Dental Education Association, Dr. James Swift.

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WEDNESDAY, MARCH 18, 2009.

**AMERICAN DENTAL EDUCATION ASSOCIATION**

**WITNESS**

**DR. JAMES Q. SWIFT**

Dr. SWIFT. Good afternoon, Mr. Chairman and members of the Subcommittee. I am Dr. Jim Swift, I am the Director of the Division of Oral and Maxillofacial Surgery at the University of Minnesota, and I am here today as the Immediate Past President of the American Dental Education Association which is also called ADEA.

Thank you for your unwavering support of the SCHIP legislation which recognized that oral health care was an important component of children's overall health care, and I also appreciate your earlier comment about the mental and dental component, of the importance of dental care to systemic health.

We request a build-upon funding of the American Economic Recovery and Reinvestment Act and your Committee's 2010 fiscal year appropriations.

We applaud, Chairman Obey, your decision to provide \$500,000,000 to address health care professional shortages and \$200,000,000 to the Title VII health professional programs and \$300,000,000 through the Recovery Act.

Additionally, President Obama's budget blueprint for 2010 builds upon the down payment made in the economic stimulus package by investing \$300,000,000 to increase the number of physicians, nurses and dentists practicing in under-served areas of this Country.

This afternoon, I would like to discuss our budget recommendations under three areas: dental education, dental research and access to oral health care. Specifically, I would like to urge Congress to provide \$16,000,000 for dental Title VII health profession programs and \$117,000,000 for Title VII diversity and student aid programs.

The dental health professional programs support general practice residency training programs as well as pediatric dental training programs to provide access to care and the training that is necessary to provide our dentists to be trained in a way to be able to access this patient population.

The diversity and student aid support will allow us to get under-represented minorities into our profession to provide care that is needed in those communities.

Secondly, we urge Congress to provide \$33,000,000,000 for the National Institutes of Health, specifically of which \$441,000,000 would be allocated to the National Institute of Dental and Craniofacial Research. I think many of you are aware of the oral systemic connection of the association of periodontal disease with cardiac disease and the utilization of salivary markers to determine

disease in disease-risk population. All these entities were studied by the NIDCR, and funding would be appropriate.

Thirdly, we recommend \$19,000,000 for the dental program Part F of the Ryan White HIV/AIDS Treatment and Modernization Act. This dental reimbursement program is a cost-effective mechanism to allow care to those individuals that need it through our dental education institutes as well as through community-based partnerships that allow the type of treatment to be rendered, to train our students to be able to render it and have an appreciation for the care that is needed and the special type of care that these patients have to have.

We also recommend \$10,000,000 for the Dental Health Improvement Act. This newly reauthorized program supports the development of innovative dental workforce programs specifically to States' specific dental workforce needs. Grants are being used to support a variety of initiatives including but not limited to loan repayment programs, to recruit culturally and linguistically competent dentists to work in under-served areas and with under-served populations.

We also request \$17,000,000 for the oral health programs at the Centers for Disease Control and Prevention which allows technical assistance to provide preventive programs with fluoridation of water as well as sealant programs to prevent disease.

Lastly, we recommend \$235,000,000 for the National Health Service Corps which allows loan repayment programs for dentists to be able to work in environments. They have significant debt when they are finished with their dental training. If they have an opportunity to repay their dental educational debts by loans, then they are more likely to go into areas where the access to care is important.

In conclusion, I want to thank the Committee for considering our budget request for dental education and research in fiscal year 2010. Any comprehensive reform of the U.S. health care system should provide universal coverage and access to high quality care of which dental is a component.

Thank you very much for the opportunity to present.

[The information follows:]



**Statement of the  
American Dental Education Association (ADEA)**

**Hearing for Fiscal Year 2010 Appropriations  
Before the  
House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies**

**Presented by  
Dr. James Q. Swift  
Professor and Director  
Division of Oral and Maxillofacial Surgery  
University of Minnesota School of Dentistry**

**March 18, 2009  
2:00 p.m.**



**Statement of the  
American Dental Education Association (ADEA)**

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Before the  
House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies**

**Presented by  
Dr. James Q. Swift  
Professor and Director  
Division of Oral and Maxillofacial Surgery  
University of Minnesota School of Dentistry**

**March 18, 2009  
2:00 p.m.**

Good afternoon, Mr. Chairman and members of the Subcommittee. I am Dr. James Swift, Director, Division of Oral and Maxillofacial Surgery, at the University of Minnesota School of Dentistry. I am a practicing oral and maxillofacial surgeon and currently serve as the Immediate Past President of the American Dental Education Association, known as ADEA. On ADEA's behalf, I am honored to appear before you to offer our recommendations with regard to fiscal year 2010 appropriations.

The American Dental Education Association represents all 58 dental schools in the United States, in addition to more than 700 dental residency training programs and nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. It is at these academic dental institutions that future practitioners and researchers gain their knowledge, where the majority of dental research is conducted, and where significant dental care is provided. ADEA member institutions serve as dental homes for a broad array of racially and ethnically diverse patients, many who are uninsured, underinsured, or reliant on public programs such as Medicaid and the Children's Health Insurance Program for their health care.

ADEA's requests build upon funding from the American Economic Recovery and Reinvestment Act (ARRA) and the Labor, Health and Human Services and Education fiscal year 2009 Appropriations. We applaud Chairman Obey's decision to provide \$500 million to address health professional shortages, \$200 million through Title VII Health Professions Programs and \$300 million in the ARRA. Additionally, President Obama's budget blueprint for FY 2010 builds upon the down payment made in the economic stimulus package by investing \$330 million to increase the number of physicians, nurses, and dentists practicing in underserved areas of the country.

This afternoon I would like to discuss our budget recommendations under three areas:

- I. Dental Education: The Title VII Health Professions Education and Training Programs and Diversity and Student Aid Programs, administered by the Health Resources and Services Administration (HRSA);
- II. Oral Health Research: The National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR); and
- III. Access to Care: The Ryan White CARE Act HIV/AIDS Dental Reimbursement Program and the Community-Based Dental Partnerships Program; the Dental Health Improvement Act; the Oral Health Program at the Centers for Disease Control and Prevention (CDC); and the National Health Service Corps (NHSC).

Specifically, the American Dental Education Association respectfully urges the Subcommittee to provide adequate funding for the continuation and enhancement of the following programs that help to address the nation's oral health care needs:

#### I. Dental Education

- **\$16 million for General Dentistry and Pediatric Dentistry Residency Training in the Title VII Health Professions Programs**

The Title VII General and Pediatric Dentistry Programs are critical to building the primary care dental workforce. Support for these programs is essential to expanding existing or establishing new general dentistry and pediatric dentistry residency programs, which have shown to be effective in increasing access to dental care for vulnerable populations, including patients with developmental disabilities, children, and geriatric patients. These primary care dental residency programs generally include outpatient and inpatient care and afford residents an excellent opportunity to learn and practice all phases of dentistry, including trauma and emergency care, and comprehensive ambulatory dental care for adults and children.

- **\$117.6 million for Diversity and Student Aid**

- **\$33.6 million for Centers of Excellence (COE)**
- **\$47.1 million for Scholarships for Disadvantaged Students (SDS)**
- **\$35.6 million for Health Careers Opportunity Program (HCOP)**
- **\$1.3 million for Faculty Loan Repayment Program (FLRP)**

The Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health professions' student body and thereby the health care workforce. Blacks, Hispanics, and American Indians currently represent more than 25 percent of the U.S. population. By the year 2050, nearly one in five Americans (19 percent) will be an immigrant, compared with one in eight (12 percent) in 2005. Despite these population trends, minorities are underrepresented in the U.S. health care workforce. This is no less true of dentistry, where they comprise less than five percent of dentists and about nine percent of dental faculty. For the last several years, these programs have not

enjoyed an adequate level of funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population.

## II. Oral Health Research

- **\$33.2 billion for the National Institutes of Health, including \$440.9 million for the National Institute of Dental and Craniofacial Research (NIDCR)**

Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for tens of millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make new breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples; and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic, and biological factors. Dental research is the underpinning of the profession of dentistry. With grants from NIDCR, dental researchers in academic dental institutions have built a base of scientific and clinical knowledge that has been used to enhance the quality of the nation's oral health and overall health.

Investments in dental research will produce inventions that make corporations more competitive in the global economy and benefit everyone with new businesses and jobs. It is important to note that NIH disproportionately creates higher-paying employment opportunities that require a higher level of technical sophistication in construction, staffing, and supporting laboratories. The average wage associated with jobs created through NIH grants and contracts was \$52,000 in 2007.

## III. Access to Dental Care

- **\$19 million for the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program, Part F of the Ryan White HIV/AIDS Treatment and Modernization Act**

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. By providing reimbursement to dental schools and schools of dental hygiene, the Dental Reimbursement Program provides access to quality dental care for people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. The Dental Reimbursement Program is a cost-effective federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Particularly important to this program is the fact that Congress designated dental care as a "core medical service" when it reauthorized the Ryan White program in 2006.

The Community-Based Dental Partnership Program fosters partnerships between dental schools and communities lacking academic dental institutions to ensure access to dental care for HIV/AIDS patients living in those areas.

- **\$10 million for the Dental Health Improvement Act (DHIA)**

This newly reauthorized program supports the development of innovative dental workforce programs specific to states' dental workforce needs and increases access to dental care for underserved populations. In FY 2006, Congress provided first-time DHIA funding of \$2 million to assist states in developing innovative dental workforce programs. The inaugural grant cycle, held in FY 2006, yielded 36 applications from states. Eighteen states were awarded grants ranging from \$67,865 to \$124,080. Grants are being used to support a variety of initiatives including, but not limited to, loan repayment programs to recruit culturally and linguistically competent dentists to work in underserved areas with underserved populations including the developmentally disabled; rotating residents and students in rural areas; recruiting dental school faculty; training pediatricians and family medicine physicians to provide oral health services (screening exams, risk assessments, fluoride varnish application, parental counseling, and referral of high-risk patients to dentists); and supporting teledentistry.

- **\$17.5 million for the Oral Health Programs at the Centers for Disease Control and Prevention**

The CDC Oral Health Program expands the coverage of effective prevention programs. The program increases the basic capacity of state oral health programs to accurately assess the needs of the state, organize and evaluate prevention programs, develop coalitions, address oral health in state health plans, and effectively allocate resources to the programs. CDC's funding and technical assistance to states is essential to help oral health programs build capacity. Increasing the funding will help to ensure that all states that apply may be awarded an oral health grant.

- **\$235 million for the National Health Service Corps (NHSC)**

The NHSC scholarship and loan repayment program provides awards to health care professionals, including dentists and dental hygienists who agree to work in underserved communities for a minimum of two years. Participants must work in a Health Professional Shortage Area (HPSA), and dentists and dental hygienists work in Dental Health Professional Shortage Areas (Dental HPSAs). As of September 30, 2008, about 48 million people lived in the 4,048 Dental HPSAs. The dedicated clinicians of the NHSC provide quality care to millions of people who would otherwise lack adequate access to health services.

In conclusion, Mr. Chairman, I thank the Committee for considering the American Dental Education Association's FY 2010 budget requests for federal agencies and programs that sustain and enhance dental education, oral health research, and access to care. A continuing federal commitment is needed to help meet the challenges oral diseases pose to the nation's most vulnerable citizens, including children. Also critical is the

development of a partnership between the federal government and dental education programs to implement a national oral health plan that guarantees access to dental care for everyone, ensures continued dental health research, and eliminates disparities and workforce shortages.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

Dr. James Q. Swift  
University of Minnesota School of Dentistry  
7-174 Moos Health Science Tower  
515 Delaware Street S.E.  
Minneapolis, MN 55455  
612-624-7937

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

**American Dental Education Association**

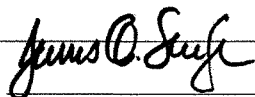
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

See Attached Document.

Signature: \_\_\_\_\_



Date: March 13, 2009

Mr. OBEY. Thank you. I appreciate it.

Let me tell the Committee that we obviously have an effective sabotage operation going on, on the House Floor. [Laughter.]

We have eight votes coming up, including a Motion to Recommit with ten minutes debate. So, when we break up, I don't have the foggiest idea when we are going to get back here. We will try to make it as quickly as we can.

Let's see how many people we can get through before, so we inconvenience as few people as possible after the vote.

Next, Academic Family Medicine Advocacy Alliance, Dr. Jerry Kruse.

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WEDNESDAY, MARCH 18, 2009.

**ACADEMIC FAMILY MEDICINE ADVOCACY ALLIANCE**

**WITNESS**

**DR. JERRY KRUSE, M.D., M.S.P.H.**

Dr. KRUSE. Mr. Chairman, members of the Committee, I am Jerry Kruse, professor and Chair of Family and Community Medicine at the SIU School of Medicine in Springfield, Illinois, and I am here on behalf of the academic family medicine organizations that are listed in the written statement.

I thank you for the opportunity to testify in support of funding for Title VII primary care medicine and dentistry and in support of funding for primary care research at AHRQ and the NIH.

The U.S. health care system is out of balance, over-reliant on specialty care, very expensive and trails the wealthy nations of the world in health care outcomes.

We know that health systems with strong foundations in primary care have the best health care outcomes, the best quality indicators, significantly lower costs, more equitable care, and they eliminate disparities in health care outcomes. Abundant evidence like this over the past 30 years proves that primary care is the essential foundation of the best health care system. So, for the best health care system, we need to train more family physicians.

We are very concerned about the production pipeline of family physicians in the United States. For the past 3 years, only 15 percent of U.S. medical school graduates chose careers in primary care, one-third of what we need to have the best system.

What can be done?

Two key steps come under the purview of this Committee: Primary care training and primary care research. So we ask your help to increase funding for key programs that work: primary care training under Title VII and primary care research at AHRQ And NIH.

So, how will increased funding in these areas help our health care system? I will give an example.

Since 2003, the funding for community health centers, CHCs, has doubled by \$2,000,000,000. The Recovery Bill has added \$1,500,000,000 to this, and this is laudable. However, over the same period of time, the funding for programs that train physicians

most likely to practice in these places, the Title VII programs, has been cut by 55 percent.

So here is an analogy. Do you think that new sports stadiums would be built if there were not a pipeline of players and coaches to attract the fans to fill the seats? No, of course, they wouldn't.

Mr. OBEY. Unless you are a Cubs fan. [Laughter.]

Dr. KRUSE. I am a Cardinals fan.

Likewise, funding for CHCs must be accompanied by corresponding significant increases funding to train and to attract family physicians and the health care professionals that are needed.

Are these programs effective? Yes. Important organizations like the Institute of Medicine, CRS, the GAO, the Medicare Payment Advisory Commission and others all testify to the fact that these programs are effective and undervalued. In addition, these programs are stimulants to local economies.

We appreciate that this Committee proposed to double the current Title VII primary care funding in the Recovery Bill, but today we don't know how much of the \$200,000,000 available will be distributed to primary care medicine and dentistry. We ask that Congress rebuild its investment in primary care medicine and add to the investment made in the Recovery Bill by providing an annual appropriation of \$215,000,000 for primary care medicine and dentistry health professions training grants.

With respect to primary care research, we are pleased with the Recovery Bill's infusion of funding for comparative effectiveness research at AHRQ, but more core funding is needed at AHRQ to fulfill its mission. We support the request of the Friends for AHRQ for base funding of \$405,000,000 annually. The Institute of Medicine believes AHRQ is critical to retooling the American health care system and goes further, recommending \$1,000,000,000 annually.

For NIH, we are encouraged by the NIH road map and the emphasis on translational research. We support an increase in NIH funding directed toward primary care research and population-based translational research. This research is key to building the type of practice that attracts and supports family physicians and improves health outcomes.

In conclusion, as the U.S. moves toward major health care reform, we urge the Committee to support programs that emphasize an increased supply of family physicians and emphasize primary care research. These programs will work together for the health of all Americans.

Thank you.

[The information follows:]



**ACADEMIC  
FAMILY  
MEDICINE  
ADVOCACY  
ALLIANCE**



Society of Teachers  
of Family Medicine



Association of  
Departments of  
Family Medicine



Association of  
Family Medicine  
Residency  
Directors



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**Jerry E. Kruse, MD, MSPH**

Professor and Chair, Department of Family & Community Medicine  
Southern Illinois University School of Medicine, Springfield IL  
Exec. Director, SIU/Blessing Hospital Quincy Family Medicine Programs,  
Quincy, IL

**Testimony  
before**

**House Appropriations Labor/HHS/Education Subcommittee  
Wednesday, March 18, 2009 2:00 PM**

**On behalf of:**

**Society of Teachers of Family Medicine  
Association of Departments of Family Medicine  
Association of Family Medicine Residency Directors  
North American Primary Care Research Group**

Dr. Kruse will be testifying on the need for a major multifaceted effort to infuse the health care system with more primary care physicians. His testimony will discuss the need for such a build-up to support Congressional efforts at health care reform. He will discuss FY 2010 funding levels for the following programs:

- **Title VII, Section 747 Primary Care Medicine and Dentistry Cluster.** The Academic Family Medicine Advocacy Alliance recommends that Congress build on the investment in primary care medicine training made in the *American Recovery and Reinvestment Act (ARRA)* by providing an appropriation of \$215 million for primary care medicine and dentistry health professions training grants. Dr. Kruse will testify about how key advisory committees know these programs are effective, how these programs are economic drivers of cost-savings and higher quality, and how important these programs are to health care reform.
- **Agency For Healthcare Research And Quality.** The Academic Family Medicine Advocacy Alliance supports the request of the Friends of AHRQ which recommends an FY 2010 base funding level of \$405 million, an increase of \$32 million over the FY 2009 level. This increase will preserve AHRQ's current initiatives and get the agency on track to a base budget of \$500 million by 2013.
- **National Institutes of Health.** The Academic Family Medicine Advocacy Alliance supports increased research related to the most common acute, chronic, and comorbid conditions that primary care clinicians care for on a daily basis is currently lacking. Primary care physicians are in the best position to design and implement research of the common clinical questions confronted in practice. Funding should be increased both for the training of primary care researchers and for this type of clinical research. Such training is necessary to impart critical research skills to the primary care workforce and to contribute to the body of knowledge necessary to put primary care on similar footing with other specialties that have established research infrastructures. Additionally, we recommend report language to help accomplish movement toward this goal.

**Scott Fields, MD**  
**President, Society of Teachers of Family Medicine**

**Jeffrey Borkan, MD, PhD**  
**President, Association of Departments of Family Medicine**

**Elissa Palmer, MD**  
**President, Association of Family Medicine Residency Directors**

**Allan Dietrich, MD**  
**President, North American Primary Care Research Group**

Testimony for the Record  
 House Appropriations Labor/HHS/Education Subcommittee  
 March 18, 2009

**FY 2010 FUNDING LEVELS**  
**SECTION 747 PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER**  
**AGENCY FOR HEALTHCARE RESEARCH AND QUALITY**  
**NATIONAL INSTITUTES OF HEALTH**

Mr. Chairman, I am Jerry Kruse, MD, MSPH, Professor and Chairman, the Department of Family and Community Medicine at Southern Illinois University. I am here on behalf of the Society of Teachers of Family Medicine, the Association of Departments of Family Medicine, the Association of Family Medicine Residency Directors, and the North American Primary Care Research Group. I thank you for the opportunity to provide this testimony in support of funding for family medicine training in health professions training, the Agency for Healthcare Research and Quality (AHRQ) and the National Institutes of Health (NIH).

***Health Care Reform Requires a Robust Primary Care Workforce:***

Health care reform without measures to address the need for more primary care physicians will never be comprehensive or effective; it will not be able to help the most vulnerable populations, and it will not address the significant cost and quality issues currently so problematic in the United States. Increased access for patients in terms of insurance coverage is critical, but not sufficient to resolve the growing shortage of primary care physicians. In fact increased coverage, without increased numbers of primary care physicians is a recipe for disaster.

Solving the problem of the primary care crisis requires a multi-faceted solution. One key element is to increase the value of primary care, both in terms of payment rates and loan forgiveness, and through other avenues to make primary care an attractive specialty choice for medical students. A second is to change the incentives and rules surrounding training under the Medicare graduate medical education (GME) system. A third is to increase funding of programs that are effective in producing more primary care physicians, such as the primary care medicine and dentistry cluster of the health professions training programs. And the fourth is to support research regarding the

clinical needs of most people seeking care, relating to the most common acute, chronic, and comorbid conditions routinely cared for by primary care physicians.

It is the latter two building blocks: funding for primary care physician training programs and funding for primary care research that come under this subcommittee's jurisdiction and that we are here to speak to today.

**Health Professions: Primary Care Medicine and Dentistry (Title VII, Section 747)**

We recommend that Congress build on the investment in primary care medicine training made in the *American Recovery and Reinvestment Act (ARRA)* by providing an appropriation of \$215 million for primary care medicine and dentistry health professions training grants. The FY 2009 omnibus appropriations bill only provided \$500,000 more for these programs than in FY2008. This funding level (\$48.4 million) is less than half of the funding these programs received in FY2003. We appreciate your efforts in that the House had proposed to double that account in the *ARRA*. We applaud the \$300 million included for the National Health Service Corps, but we do not know how the remaining \$200 million in workforce funds will be distributed between the many other workforce programs included in the *ARRA*.

***Key Advisory Committees Know These Programs are Effective:***

- The **Institute of Medicine (IOM)** calls the Title VII program an “undervalued asset.” Title VII, section 747, administered by HRSA, is the only program aimed directly at training primary care physicians. On December 12, 2008, the Institute of Medicine released “HHS in the 21st Century: Charting a New Course for a Healthier America,” which points to the drastic decline in Title VII funding. Within that report, the IOM terms Title VII an “undervalued asset.”
- The **HRSA Advisory Committee on Training in Primary Care Medicine and Dentistry**<sup>1</sup> recommends an annual minimum level of \$215 million for the Title VII, section 747 grant program. The Committee reasoned that:

*Title VII funds are essential to support major primary care training programs that train the providers who work with vulnerable populations ... additional funding is also necessary to prepare current and future primary care providers for their critical role in responding to healthcare challenges including demographic changes in the population, increased prevalence of chronic conditions, decreased access to care, and a need for effective first-response strategies in instances of acts of terrorism or natural disasters.*

- The **Congressional Research Service (CRS)** also found that reduced funding for the primary care medicine and dentistry cluster had a deleterious impact on the effectiveness of these programs – at a time when more, rather than less primary care is needed. For example, “In FY2006, the program supported a total of 17,870 individuals in clinical

<sup>1</sup> *The Role of Title VII, Section 747 in Preparing Primary Care Practitioners to Care for the Underserved and Other High-Risk Groups and Vulnerable Populations*. Sixth Annual Report to the Secretary of the U.S. Department of Health and Human Services and to Congress

training in underserved areas, a decrease from the support of 31,153 individuals in FY2005.<sup>2</sup> This is a decrease of almost 43%, in only one year.

- A study in the *Annals of Family Medicine* (September/October 2008) shows that medical schools that receive primary care training dollars produce more physicians who work in Community Health Centers (CHCs) and serve in the National Health Service Corps (NHSC) compared to schools without Title VII primary care funding. In spite of an effort to double the capacity of CHCs between 2002 and 2006, CHCs have found it difficult to recruit a sufficient number of primary care physicians and have hundreds of vacant positions.

***Programs are Economic Drivers of Cost-savings and Higher Quality***

- A *Health Affairs* (April 2004) article found a lower quality of care in states with higher levels of Medicare spending. The authors from the Dartmouth Center for the Evaluative Clinical Sciences found that states with more specialists and fewer primary care physicians had significantly higher costs and lower quality. A small increase in the number of primary care physicians in a state was associated with a large boost in that state's quality ranking. Indeed, states at the 75<sup>th</sup> percentile in number of primary care physicians per capita recorded Medicare costs \$1600 less per Medicare beneficiary per year and higher quality indicators than states at the 25<sup>th</sup> percentile. If all states were to move to this level of primary care services, higher quality care could be delivered at a savings of \$60 billion or more per year for Medicare patients alone. Increased funding for Title VII, section 747 could train more family doctors to be available to provide this much needed high-quality, lower-cost care.
- The **Government Accountability Office (GAO)** and the **Medicare Payment Advisory Commission (MedPAC)** have noted research indicating that access to primary care is associated with better health outcomes and lower health care costs. The GAO states "Ample research in recent years concludes that the nation's over reliance on specialty care services at the expense of primary care leads to a health care system that is less efficient. At the same time, research shows that preventive care, care coordination for the chronically ill, and continuity of care --- all hallmarks of primary care medicine -- **can achieve improved outcomes and cost savings.**"<sup>3</sup>[emphasis added]
- According to a report prepared by the **National Association of Community Health Centers, The Robert Graham Center, and Capitol Link**<sup>4</sup>, "There is a growing consensus among the nation's political and industry leaders that the U.S. health care crisis has shifted from the realm of the poor and disenfranchised, to the doorstep of middle-class America." Additionally, they cite the following:

<sup>2</sup> CRS Report to Congress. February 7, 2008 Title VII Health Professions Education and Training: Issues in Reauthorization (Order Code RL32546)

<sup>3</sup> Testimony before the Committee on Health, Education, Labor, and Pensions, U.S. Senate. Primary Care Professionals: Recent Supply Trends, Projections and Valuation of Services. Statement of A. Bruce Steinwald, Director Health Care, United States Accountability Office. February 12, 2008 GAO-08-472T

<sup>4</sup> Access Granted: The Primary Care Payoff, August 2007, National Association of Community Health Centers, The Robert Graham Center, Capitol Link (pgs 1-2)

*"If every American made use of primary care, the health care system would see \$67 billion in savings annually. This reflects not only those who do not have access to primary care, but also those who rely extensively on costly specialists for most of their care, leading to inefficiencies in the system. More specifically, the expansion of Medical homes can even more dramatically facilitate effective use of health care, improve health outcomes, minimize health disparities, and lower overall costs of care."*

- Another study by the **Robert Graham Center**<sup>5</sup>, found that the economic impact of one family physician to his or her community was just over \$900,000 annually. Family physicians are the specialty most widely distributed throughout the US. Using the data from their study on the economic impact of family physicians in their communities, they estimate that family physicians generate a nationwide economic impact of more than \$46 billion per year. This is a conservative estimate, and does not include a number of intangible and other tangible economic benefits of family physicians, such as their contribution to the generation of income for other local health care organizations such as hospitals and nursing homes. In addition, while most medical specialties tend to cluster in urban areas and near academic health centers, family physicians are the specialists that are most likely to work in the poorest rural and urban areas. These underdeveloped geographies are also the ones most likely to be medically underserved.
- Multiple studies from the **Johns Hopkins Bloomberg School of Public Health** have demonstrated that disparities in health care outcomes due to income inequality and socioeconomic status are reduced when there is an adequate supply of primary care.

**The Agency for Health Care Research and Quality (AHRQ) and the Institutes of Health (NIH) – Health Care Reform Requires New Areas of Endeavor**

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians care for on a daily basis is currently lacking. Primary care physicians are in the best position to design and implement research of the common clinical questions confronted in practice. Funding should be increased both for the training of primary care researchers and for this type of clinical research. Such training is necessary to impart critical research skills to the primary care workforce and to contribute to the body of knowledge necessary to put primary care on similar footing with other specialties that have established research infrastructures. We are pleased with the infusion of funding through the ARRA for comparative effectiveness research, but there is a need to provide new funding directly toward specific clinical and translational endeavors.

**AHRQ:** AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. While targeted funding increases in recent years have moved AHRQ in the right direction, more core funding is needed to help AHRQ fulfill its mission. We support the request of the Friends of AHRQ which recommends an FY 2010 base funding level of \$405 million, an increase of \$32 million over the FY 2009 level. This increase will preserve AHRQ's current initiatives and get the agency on track to a base budget of \$500 million by 2013.

<sup>5</sup>The Family Physician as Economic Stimulus, <http://www.graham-center.org/online/graham/home/tools-resources/directors-corner/dc-economic-stimulus.html>

The Institute of Medicine's report, *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century* (2001) recommended a much larger investment in AHRQ. It recommended \$1 billion a year for AHRQ to "develop strategies, goals, and action plans for achieving substantial improvements in quality in the next 5 years..." AHRQ is critical to retooling the American health care system.

One of the hallmarks of the Patient-Centered Medical Home is evidence-based medicine. Comparative effectiveness clinical research, compares the impact of different options for treating a given medical condition, and is vital to improving the quality of health care. Studies comparing various treatments (e.g. competing drugs) or differing approaches (e.g. surgery vs. drug therapy) can inform clinical decisions by analyzing not only costs but the relative medical benefits and risks for particular patient populations.

**NIH:** Historically, the NIH has placed little emphasis on the research questions asked by primary care physicians and in primary care settings. We have been encouraged by the development of the NIH Roadmap and the Clinical and Translational Science Awards (CTSA), along with the establishment, in statute, of a funding stream that would make NIH more relevant to where most people receive care. We support an increase in NIH funding. In addition, we would like to see some report language that would help NIH ensure that the promise of "bench to bedside" research truly becomes "bench to bedside to community" – and community to bedside to bench.

We support the inclusion of the following language in the report to accompany the Labor/HHS appropriations bills for FY10:

*"Translational Research has been identified by the former Director of the National Institutes of Health (NIH) as a road map initiative. The committee supports this effort and encourages NIH to integrate such research as a permanent component of the research portfolio of each institute and center. The committee urges NIH to work with the primary care community to determine how best to facilitate progress in translating existing research findings and to disseminate and integrate research findings into community practice. Translational research should also include the discovery and application of knowledge within the practice setting using such laboratories as practice-based research networks. This research spans biological systems, patients, and communities, and arises from questions of importance to patients and their physicians, particularly those practicing primary care. The Committee requests that the Director of NIH include a progress update in next year's Budget Justification."*

**Conclusion:**

As the US moves toward major health care reform, we urge the committee to support programs needed to ensure the proper supply of primary care physicians and the type of research that will work together to improve health care outcomes, enhance equity in care, and lower health care costs. We support increases in these three important programs: health professions primary care medicine and dentistry training, AHRQ, and NIH.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

**Jerry E. Kruse, MD, MSPH**

Professor and Chair, Department of Family & Community Medicine

Southern Illinois University School of Medicine

911 N. Rutledge, Springfield IL 62794-9671 (217) 545-0200

Executive Director, SIU/Blessing Hospital Quincy Family Medicine Programs

612 N. 11<sup>th</sup> St., Quincy IL 62301 (217) 224-9484

E-Mail: [jkruse@siumed.edu](mailto:jkruse@siumed.edu) Fax: (217) 224-7950

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Society of Teachers of Family Medicine

Association of Departments of Family Medicine

Association of Family Medicine Residency Directors

North American Primary Care Research Group

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes ☐ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

The Society of Teachers of Family Medicine received the following grant:

Grant #: 5 G08 LM007889-03

Dept of Health & Human Services, National Institutes of Health, National Library of Medicine

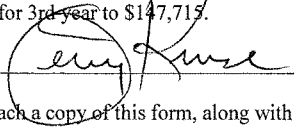
Principal Investigator: Sherwood, Roger A CAE

Project Title: Family Medicine Digital Resources Library (FMDRL)

Budget Period: 9-30-2006 - 9-29-2007

Amount of 3rd year award: \$127,008

Note: We received approval of un-obligated carry over funds in the amount of \$20,707 bringing total budget for 3rd year to \$147,715.

Signature:  Date: 3/18/08

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. Thank you very much.

Now let me call on Congresswoman Lowey.

Mrs. LOWEY. Well, thank you. And I am sorry I couldn't be here, but, thank you, Chairman Obey, for giving me the privilege of introducing Lindsay Farrell who works fast, talks fast, is doing a great job in one of my community health centers, and I am very proud of her.

Lindsay, your work has been an absolutely critical part of the strategy to keep our community healthy, and we all thank you so much for appearing before us today.

Thank you, Chairman Obey.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL ASSOCIATION OF COMMUNITY HEALTH  
CENTERS**

**WITNESS**

**LINDSAY FARRELL**

Ms. FARRELL. Thank you, Congresswoman Lowey, Chairman Obey, Ranking Member Tiahrt, members of the Subcommittee.

I am the President and CEO of Open Door Family Medical Center located in the suburbs north of New York City in Westchester County. We operate 8 health centers and serve 32,000 patients.

While Westchester is one of the wealthiest counties in the Country, the income disparity between the rich and the poor is huge. More than 55 percent of our patients have no health insurance whatsoever. The rest of our patients are covered by essential programs like Medicaid, SCHIP and Medicare. A small number are covered by commercial insurance, only 3 percent, provided through their employers.

And so, on behalf of Open Door as well as the 18 million patients served by community health centers nationwide, I want to thank you for your unyielding support and for your dedication to our mission of providing affordable, accessible primary health care to all Americans. In this time of enormous challenges for our health care system and our economy, your faith in us and your support through the Recovery Act will allow us to rise and meet the challenges and continue to excel.

Over more than 40 years, the Health Centers Program has grown to become a critical component of our Nation's primary care infrastructure.

My health center serves as the family doctor and dentist to people who would otherwise have to seek care in hospital emergency rooms. Because we are open six days a week and evenings or we are on call 24 hours a day, we prevent countless non-urgent emergency room visits.

Open Door is also dedicated to comprehensive primary and preventive care. For example, we provide our State's prenatal care assistance program. Our obstetricians and midwives delivered nearly 600 babies last year.

At Open Door, doctors, dentists, nutritionists and social workers all work as a health care team under one roof. We are a health



care home that provides an array of health screenings, works to prevent disease and treat illnesses, but, importantly, we also strive to engage patients so that they will do what they need to in order to be healthy. We know this is the best way to use health care dollars effectively.

We sincerely appreciate the funding increases for the Health Centers Program that the Subcommittee has approved over the last several years. This expansion has brought access to care to millions who were previously medically disenfranchised.

Despite this record expansion, hundreds of communities have submitted high-quality applications over the past few years for a new health center that could not be funded. An investment of \$2,600,000,000 for the Health Centers Program in fiscal 2010, the level authorized in the recently enacted Health Care Safety Net Act, could expand care to millions of new patients.

Carving out \$66,000,000 of that increase for base grant adjustments for existing centers would ensure that we keep pace with rising health care costs and increasing numbers of under-served patients.

This funding will also keep the Health Centers Program on a path toward reaching our goal of servicing 30 million patients by 2015.

I know that the members of the Subcommittee are well aware that the Health Centers Program is an unprecedented health care success story. However, the reason I am most proud to be here representing health centers nationwide is my own center and the way we are transforming health care at the grassroots.

Health centers sit at the intersection of private practice and public health. We are unique in our vantage point and have much to contribute to the debate over health care reform.

As Mrs. Lowey heard at her meeting on Monday, I know you forced to make difficult decisions in these tough times. However, health centers provide a documented value to the government and to all who benefit from our services. Please continue your outstanding support of our efforts once again this year.

Thank you.

[The information follows:]

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**Lindsay C. Farrell**

President and CEO, Open Door Family Medical Center, Inc.

Westchester County, New York

Wednesday, March 18, 2009 2:00 pm

**Representing:**

Open Door Family Medical Center, Inc.

and the National Association of Community Health Centers, Inc.

**Topic:**

Ms. Farrell will speak in support of increased funding for the Community Health Centers program. The Health Centers program is a part of the Department of Health and Human Services' (HHS) Health Resources and Service Administration (HRSA). Ms. Farrell's testimony will indicate how in her personal experience as President and CEO of Open Door Family Medical Center, Inc. continued expansion of the Health Centers program will provide much needed health care access to underserved areas and populations, improve health, reduce costs, and enhance value in the health care system overall.

**Testimony of Ms. Lindsay C. Farrell**  
President and CEO, Open Door Family Medical Center, Inc.  
Before the House Appropriations Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies  
Wednesday, March 18, 2009 2:00pm  
Room 2358 of the Rayburn House Office Building

**Introduction**

Chairman Obey, Ranking Member Tiahrt, and Members of the Subcommittee:

My name is Lindsay Farrell, and I am the President and CEO of Open Door Family Medical Center, Inc. We are located in the suburbs north of New York City in Westchester County, New York where we operate eight health centers and serve 32,000 patients. What is interesting is that Westchester is one of the wealthiest counties in the Country, yet income disparity between the rich and poor is huge-- more than 55% of the people served by Open Door have no health insurance what so ever. The rest of our patients are covered by essential government programs like Medicaid, SCHIP, and Medicare and only a small number (3%) are covered by commercial insurance provided through their employers.

And so, on behalf of the 18 million patients served by community health centers nationwide, as well as the volunteer board members, staff, and countless members of the health center movement, I want to thank you for this Subcommittee's unyielding support for health centers and your dedication to the health center mission of providing affordable, accessible primary health care to all Americans. In this time of enormous challenges in our health care system and our economy, your faith in us and your support through the Recovery Act will allow us to rise and meet these challenges and continue to excel. With your ongoing support, our cost-effective, high quality system of care can continue to expand, reaching 30 million Americans by 2015.

**About Community Health Centers**

Over more than forty years, the Health Centers program has grown from a small demonstration project to an essential element of our nation's primary care infrastructure.

Today, health centers serve as the primary health care safety net in thousands of communities and, thanks to your support, the federal Health Centers grant program enables more low-income and uninsured patients to receive care each year. Health centers currently serve as the family doctor and health care home for one in eight uninsured individuals, and one in every five low-income children. Health centers are helping thousands of communities address a range of increasing (and costly) health problems, including prenatal and infant health development, childhood obesity, chronic illnesses, mental health, substance addiction, oral health, domestic violence and HIV/AIDS.

Federal law requires that every health center be governed by a patient majority board, which means care is truly patient-centered and patient-driven. Health centers must be located in a federally designated Medically Underserved Area (MUA), and must provide comprehensive primary care services to anyone who comes in the door, regardless of ability to pay. Because of these characteristics, the insurance status of health center patients differs dramatically from other primary care providers. As a result, the role of public dollars is substantial. Federal grant dollars, which make up roughly twenty-one percent of health centers' operating revenues on average, go towards covering the costs of serving uninsured patients and delivering care effectively to our medically underserved patients. Just over 40% of health centers' revenues are from reimbursement through federal insurance programs, principally Medicare and Medicaid. The balance of revenues come from State and community partnerships, privately insured individuals, and low-income uninsured patient's sliding-fee payments.

#### **About Open Door Family Medical Center and Its Importance to Our Area**

Open Door is an essential health care provider in Westchester County because we are the family doctor and dentist to people who otherwise would have to seek care in our local hospital emergency rooms. As you can imagine, our three hospital partners are tremendously supportive of Open Door because we are open six days a week and evenings, we are on call 24 hours a day and as a result, we prevent non-urgent emergency room visits. Additionally we provide our State's Prenatal Care Assistance Program; our obstetricians and midwives delivered nearly 600 new babies last year. Further, our dentists and hygienists are deeply committed to prevention and use precious resources wisely- we have sealed the vast majority of our children's molar teeth

so they won't grow up with a mouth full of cavities. Our nutritionists too are determined to educate about the importance of eating the right foods and the lifetime benefits this will provide to every family. At Open Door, doctors, dentists, nutritionists and social workers all work as a health care team all together under one roof. We are a "health care home" that provides immunizations and an array of health screenings, works to prevent disease, and treat illnesses. But importantly, we also strive to engage patients so that they will do what they need to in order to be healthy. We know this is the best way to use health care dollars effectively.

#### **Funding Background**

I know I speak for health centers nationwide when I say how deeply we appreciate the funding increases for the Health Centers program that the Subcommittee has approved over the last several years. This expansion effort has brought access to care to millions who were previously medically disenfranchised. Since 2001, this Subcommittee has nearly doubled the investment in the Health Centers program. In that time more than 2,600 new health center sites have been created, and more than 8 million new underserved patients have gained access to care in a health center. In addition to an overall funding increase, the Subcommittee has also recognized the importance of keeping existing centers stable by providing base grant adjustments. I urge you to continue to support this balanced approach which maintains support for existing centers while expanding the health centers program to serve new patients and enhance services.

The importance of increased funding that balances our need for base grant growth and expansion is demonstrated in my own health center. Because we have been caring for increasing numbers of uninsured patients over the last ten years, our base funding simply has not kept pace with patient demand and rising costs. While we pursue every competitive grant opportunity we can in order to continue to enhance and expand our services, and we do a tremendous amount of private fundraising to bring in as much additional revenue as we can, we have no other stable source of funds that allow us to keep our services accessible to all who need them. Further, increasing costs—most notably employee health insurance and highly competitive nursing salaries- have placed a huge burden on the expense side. Base grant adjustments are absolutely essential in allowing maximum access for the uninsured of our community.

**Reauthorization**

The importance of continuing the health centers expansion has also been recognized by the Congress as whole. Late last year, in the culmination of a multi-year process, Congress unanimously passed the Health Care Safety Net Act of 2008. This legislation contains specific funding targets, which, if realized would grow health centers across the country to serve 30 million patients by 2015. We were immensely proud that this legislation garnered unanimous support in both chambers of Congress, and was signed by former President Bush. When he was in the Senate, President Obama was also an original co-sponsor of this legislation.

**This Year's Request**

Despite the record expansion of the health centers program, hundreds of communities have submitted applications for a new health center over that last few years that received very high scores, but could not be funded due to lack of funds. You recognized the overwhelming need and enthusiastic desire in countless communities to expand these valuable health care services with your support for operations funding in the Recovery Act. With additional resources, health centers stand ready to provide our low-cost, highly effective care to millions more individuals and families in need. Health centers also look forward to health reform, and we are eager to do our part to ensure that with improved coverage, there is also access to care. Increased resources for health centers will help to grow the primary care infrastructure that is essential to ensuring that the government's investment in reform translates into improved health and wellness for the nation.

An investment of **\$2.602 billion** for the Health Centers program in Fiscal Year 2010, the authorized level, could expand this system of care to millions of new patients. Carving out **\$66 million** of that increase for base grant adjustments for existing health centers would ensure that these centers can keep pace with rising health care costs and rising numbers of underserved patients. This level of funding in FY2010 will also keep the Health Centers program on a path towards reaching our collective goal, embodied in the Health Care Safety Net Act, of reaching 30 million patients by 2015.

**Conclusion**

I know that the members of this Subcommittee are well aware that the Health Centers program is an unprecedented health care success story. Entities ranging from OMB to IOM to GAO have recognized the efficiency and effectiveness of our model. There are also countless published studies that demonstrate our excellence in chronic disease management, our ability to reduce health disparities, lower costs, and generally improve outcomes across demographic lines and in a variety of communities.

However, the reason I am most proud to be here as the representative of community health centers nationwide and my own center, Open Door, is the way we are transforming health care at the grass roots where we sit at the intersection of private practice and public health. Health centers are unique in their vantage point and have much to contribute to the debate over health care reform as a result. For example, because we have to do a tremendous amount of reporting about our clinical outcomes to HRSA, Open Door implemented an electronic medical records system about a year and a half ago. Today we are realizing the benefits of mining our data to improve clinical practice. Thanks to HRSA, we are JCAHO Accredited and quite effective at change management and Performance Improvement. We monitor our clinical care relentlessly to be sure we are always following evidenced based standards and we publish a clinical report card regularly to tell the community how well we are doing. We look forward to sharing this data with other medical practices (the way they do in Wisconsin in Congressman Obey's district) and pushing for greater transparency among our medical colleagues. Changing the "medical ecology" is not as easy as it sounds but at Open Door we believe we will be an agent for change by giving patients much more information about how well we are delivering value to our community and the patients who rely on us.

I know the very difficult funding decisions you are forced to make in these tough times. However, health centers provide a true, documented value to the government and to all who benefit from their services. Please continue your outstanding support our efforts once again this year.

**PRESIDENT & CEO**

Lindsay Farrell, MBA, FACMPE was appointed President and Chief Executive Officer by the Board of Directors in October 1998. Since that time, Open Door has grown significantly adding new sites, programs and technologies to more than double the number of low-income people served. Home-grown at Open Door where she volunteered initially and has worked since 1986, Ms. Farrell has been Open Door's Director of Operations and Director of Development. As Director of Development, she was responsible for capital fund drives for major facility expansions. As the Director of Operations, she led the center's first JCAHO accreditation. At the request of the Bureau of Primary Health Care, Ms. Farrell was a member of the expert panel initiating the patient visit redesign collaborative directed by the Bureau's Quality Center; she has significant experience and a commitment to efficient health center operations and population health management.

Ms. Farrell is a member of the Board of Directors of the Community Health Care Association of New York State, Hudson Health Plan, Bronx/Westchester Area Health Education Center and of the Port Chester Council of Community Services. She is also a member of the Board of Directors of the Florida Health Choice Network. She was Chair of the Westchester Women's Agenda.

Ms. Farrell is a graduate of St. Lawrence University and received her Masters in Business Administration from the Lubin School of Business at Pace University. She is a Fellow in the American College of Medical Practice Executives and is a professional papers grader. She has received the Betsey Cook Grassroots Advocacy Award from the National Association of Community Health Centers, the Paul Ramos Memorial Award from the Community Health Care Association and New York State and the Sol Feinstein Humanitarian Award from St. Lawrence University. In December 2008, Westchester Magazine selected Ms. Farrell as one of Westchester County's most influential residents.



**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

**Lindsay C. Farrell**  
President & CEO  
Open Door Family Medical Center, Inc.  
165 Main St  
Ossining, New York 10562-4702  
(914) 502-1450

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Open Door Family Medical Center, Inc.  
National Association of Community Health Centers, Inc.


2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ **Yes**      ☐ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

*See attached form*

Signature:



Date:

3/18/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

2009

Open Door FMC		NACHC
\$2,998,596	BPHC	
\$237,196	HIV/AIDS Bureau	
\$328,580	CDC	
\$100,000	SAMHSA	

2008

Open Door FMC		NACHC	
\$2,998,596	BPHC	\$5,688,721	BPHC
\$237,196	HIV/AIDS Bureau	\$5,877,618	Corp. for National Service
\$334,422	CDC	\$165,976	CDC
\$100,000	SAMHSA	\$735	AHRQ
\$50,000	STOP Act		

2007

Open Door FMC		NACHC	
\$2,969,861	BPHC	\$6,375,677	BPHC
\$237,196	HIV/AIDS Bureau	\$6,106,614	Corp. for National Service
\$334,422	CDC	\$15,139	FDA
\$114,121	SAMHSA		

Mr. OBEY. Thank you very much.

And next—I am going to try to get at least one more in before we have to run to the Floor—National Black Nurses Association, Dr. Debra Toney.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL BLACK NURSES ASSOCIATION, INC.**

**WITNESS**

**DR. DEBRA A. TONEY, PH.D., R.N.**

Ms. TONEY. Good afternoon, Mr. Chairman and members of the Subcommittee.

The National Black Nurses Association requests \$215,000,000 for Title VIII, the Nursing Workforce Development Program.

For 11 years, our Nation has faced a critical nursing shortage which is expected to last through the next decade. This shortage threatens the safety and well being of the patients whom we are charged to care for in our health care systems. The nursing shortage only exacerbates health disparities among people of color, especially women and children.

A study by Dr. Peter Buerhaus and others estimates that a half million new nurses will be needed by 2025. The U.S. Bureau of Statistics estimates that over 140,000 nursing positions remain vacant in hospitals, nursing homes, health departments, community health centers, schools and other work places. Using the State of California as an example, it is estimated that the State would have a nursing shortage of 12,000 by 2014.

Many factors contribute to the nursing shortage including: an aging nursing workforce with the average age of a nurse being 47 years old, 66 percent of the nurse faculty is expected to retire in the next 5 to 15 years, an aging population demanding access to high quality, culturally competent health and nursing care, a population that has preventable chronic diseases that overwhelm the nursing workforce and health care systems, leading to high health care costs.

An investment in Title VIII will support the education and training of registered nurses at all levels including advanced practice nurses, nurse faculty and nurse scientists. The use of advanced practice nurses is critical to the elimination of health disparities, managing chronic disease and promote adoption of culturally relevant self-care management practices. We must provide funding to ensure an adequate pipeline of advanced practice nurses if we are going to improve access to healthcare.

Funding for the Nurse Education Loan Repayment Program is essential as it allows for new nursing graduates to enter health facilities deemed to have critical shortages such as departments of public health, community health centers and disproportionate share hospitals.

Funding for the education of nurses of diverse backgrounds is vital to improving the delivery of culturally competent nursing care to close the health disparities gaps. Studies have shown that people

are more comfortable receiving care from providers of similar ethnic and cultural background.

In the academic year 2005–2006, the National League for Nursing found that 88,000 applicants were turned away because of the lack of capacity such as lack of faculty, lack of technology, low salaries, classroom space, laboratories and limited clinical education sites. Hospitals and other facilities that are already understaffed cannot handle the patient workload and facilitate the training of nursing students.

It has been found in California State Schools of Nursing that there are more qualified students than there are slots. Moreover, California associate degree nursing schools use a lottery system to admit applicants because there are more applicants than there are openings.

In a report by the National Black Nurses Foundation it was found that because of the nursing shortage, patient safety issues become more frequent, there are longer waits for clinical appointments and admissions into hospitals, staffing for acute care beds are declining, more medical errors occur, and failure to rescue events go up.

Without interventions by nurses, the health disparities gap will only increase.

NBNA is requesting \$175,000,000 for the National Institute of Nursing Research. Nurse scientists conduct clinical and behavioral research that may be translated into nursing practice. These effective interventions improve quality of life, offer approaches for self management, symptom management and care giving.

Moreover, there is a need for more nurses to be trained to design, implement and lead clinical trials.

I appreciate your time today.

[The information follows:]

**Testimony of Debra A. Toney, PhD, RN  
President  
National Black Nurses Association  
Las Vegas, Nevada  
Before the Committee on Appropriations  
Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies  
March 18, 2009  
2 P.M.**

**Discussion topic: Title VIII, the Nursing Workforce Development  
Programs; National Institute of Nursing Research; and, Health  
Disparities**

Good afternoon, Mr. Chairman and Members of the Subcommittee,

The National Black Nurses Association applauds President Obama for his commitment to strengthening, health professional education, community health and the public health infrastructure.

The National Black Nurses Association (NBNA) requests \$215 million for Title VIII, the Nursing Workforce Development Program. For 11 years, our Nation has faced a critical nursing shortage, which is expected to last through the next decade. This shortage threatens the safety and well being of the patients whom we are charged to care for in our health care systems. The nursing shortage only exacerbates health disparities among people of color, especially women and children.

A HRSA report in 2004 projects the need for 1 million nurses, of which only 64 percent will be met. Another study by Dr. Peter Buerhaus and others estimates that a half million new nurses will be needed by 2025. The U.S. Bureau of Statistics estimates that over 140,000 nursing positions remain vacant in hospitals, nursing homes, health departments, community health centers, schools and other work places. Using the State of California as an example, it is estimated that the State would have a nursing shortage of 12,000 by 2014.

Many factors contribute to the nursing shortage including:

- an aging nursing workforce with the average age of a nurse being 47 years old.
- 66 percent of the nurse faculty is expected to retire in the next 5-15 years, and not enough nursing students are in the pipeline to fill their roles.
- an aging population, demanding access to high quality, culturally competent health and nursing care.
- a population that has preventable chronic diseases that overwhelm the nursing workforce and healthcare systems, leading to higher healthcare costs.

An investment in Title VIII will support the education and training of registered nurses at all levels, including advanced practice nurses, nurse faculty and nurse scientists.

The National Black Nurses Association calls on the President and Congress to strengthen America's public and community health infrastructure. Too many uninsured and underinsured people go without primary care or delay utilization of the health care system due to costs and inequitable treatment.

The use of Advanced Practice Nurses is critical to widening the nation's safety net and providing equitable timely primary health care services. These services can contribute to

our national goals to eliminate health disparities, manage chronic disease and promote adoption of culturally relevant self care management practices. We must provide funding to ensure an adequate pipeline of advanced practice nurses if we are going to improve access to healthcare.

Funding for the Nurse Education Loan Repayment Program is essential as it allows for new nursing graduates to enter health facilities deemed to have critical shortages such as departments of public health, community health centers and disproportionate share hospitals.

Funding for the education of nurses of diverse backgrounds is vital to improving the delivery of culturally competent nursing care and to closing the health disparities gap. Studies have shown that people are more comfortable receiving care from someone of similar ethnic and cultural background.

In the academic year 2005-2006, the National League for Nursing found that 88,000 applicants were turned away because of the lack of capacity, such as, lack of faculty, lack of technology, low wages, classroom space, laboratories and limited clinical education sites. Hospitals and other facilities that are already understaffed cannot handle the patient workload and facilitate the training of nursing students.

It has been found in California State schools of nursing that there are more qualified students than there are slots. Moreover, many California associate degree nursing schools use a lottery system to admit applicants because there are more qualified applicants than there are openings.

Increasing the level of funding for nursing education has a direct correlation to eliminating health disparities particularly among communities of color and the Nation.

In a report by the National Black Nurses Foundation it was found that because of the nursing shortage patient safety issues become more frequent.

- There are longer waits for clinical appointments and admissions into hospitals
- More medical errors occur
- Staffing for acute care beds are going down, and
- Failure to rescue events go up

Without interventions by nurses, the health disparities gap will only increase.

The National Black Nurses Association is requesting \$175 million for the National Institute of Nursing Research. Nurse scientists conduct clinical and behavioral research that may be translated into nursing practice to improve the quality of care in vulnerable populations. Establishing initiatives to eliminate health disparities that include partnering with organizations like the National Black Nurses Association and the National Coalition of Ethnic Minority Nurse Associations is critical in conducting research related to equality in healthcare. Financial support is needed to create

relationships with Historically Black Colleges and Universities and other minority serving institutions that address research and training directed at the elimination of health disparities. These effective interventions “improve quality of life, offer approaches for self management, symptom management and care giving”.

Moreover, there is a need for more nurses to be trained to design, implement and lead clinical trials. Nurses are an integral part of the clinical trials team, recruiting patients, implementing protocols, educating patients, helping them with compliance issues related to their medical regimens, providing follow-up and consultative services.

Our nation must be strategic and intentional about racial and gender focused clinical trials that are conducted with minority patient populations and communities. These clinical trials should include nurse lead projects and collaborative interdisciplinary partnerships.

Mr. Chairman and Members of the Committee, I thank you for the opportunity to testify before you this afternoon.



**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

**Dr. Debra A. Toney**  
**4535 West Sahara, Suite 209**  
**Las Vegas, Nevada 89102**  
  
**702-596-2115**

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

**National Black Nurses Association, Inc.**

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes      No      **X**

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

**N/A**

Signature: *Debra A. Toney*      Date: March 16, 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**Debra A. Toney, PhD, RN  
President and CEO  
TLC Health Care Services, Inc.**

Dr. Debra A. Toney a nurse entrepreneur is the President and CEO of TLC Health Care Services, Inc. in Las Vegas, Nevada, a licensed home health care agency specializing in skilled nursing and supportive care services. Dr. Toney created this organization, for the delivery of culturally competent nursing care, targeted to inner city senior clients. In twelve years of its existence, TLC Health Care Services has provided services to over 10,000 patients. TLC is one of only five nurse owned corporations of its type in the state of Nevada. Dr. Toney's commitment to quality health care and her belief that people recover better in their own home was the catalyst for her to develop TLC.

Dr. Toney obtained the following degrees; B.S in nursing from the University of Oklahoma, in Norman, Oklahoma, M.S. in health services administration from the University of St. Francis, in Joliet, Illinois, and a Ph.D. in human services with a specialization in health care administration from Capella University, in Minneapolis, Minnesota. Dr. Toney is a Robert Wood Johnson Executive Nurse Fellow.

Dr. Toney is active in professional organizations. She is the President of the National Black Nurses Association, a member of the American Nurses Association, Southern Nevada Black Nurses Association, Nevada Nurses Association, board member for the National Coalition of Ethnic Minority Nurse Associations and chair of the advisory committee for the Nevada State Office of Minority Health. Most recently she was appointed by the Nevada Majority Leader, Senator Steven Horsford to serve on the Health Reform Policy Council. She serves on the Nominating Group of the U.S. Food and Drug Administration, is a member of the National Institutes of Health Advisory Committee on Research on Women's Health and the Expert Advisory Panel for The Joint Commission to develop culturally competent hospital standards.

Dr. Toney is involved with a variety of community-based organizations including: Alpha Kappa Alpha Sorority, Links, Inc., A.L. Pollard Foundation, and the Ovarian Cancer Association of Nevada. She is the President of the Jourdan Kasey/Karen Lazarus Foundation named after her younger sister and is dedicated to raising awareness and educating others regarding early detection of ovarian cancer.

Dr. Debra Toney has been recognized for her contributions to society by numerous organizations such as The American Legacy Magazine's Multicultural Healthcare Award.

She is published and frequently speaks on leadership, nursing workforce, health disparities, health policy and clinical practice issues at the national and local levels. Dr. Toney is a visionary and uses her health care knowledge to help the underserved. Throughout Dr. Toney's career she has been an advocate for the underserved and actively involved with issues related to minority health, health policy and community service.

Mr. OBEY. Thank you very much.  
 Next, National Alliance of State and Territorial AIDS Directors,  
 Heather Hauck.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL ALLIANCE OF STATE AND TERRITORIAL  
 AIDS DIRECTORS**

**WITNESS**

**HEATHER HAUCK**

Ms. HAUCK. Good afternoon, Mr. Chairman and members of the Subcommittee.

My name is Heather Hauck. I am the Director of the Maryland Department of Health and Mental Hygiene's AIDS Administration. I am also the incoming Chair of the National Alliance of State and Territorial AIDS Directors, NASTAD. We represent AIDS directors and adult viral hepatitis coordinators in all States and territories in the United States.

Thank you for inviting us to address you today. State AIDS directors appreciate the opportunity to highlight the needs of State HIV, STD and viral hepatitis public health programs and thank the Subcommittee for its longstanding support of these programs.

State and local health department HIV programs work to eliminate health disparities based on race, ethnicity, gender, sexual identity and class. HIV prevention and care efforts must be aligned to meet the needs of those who bear the greatest HIV burden in our United States.

As you are aware and as has been eluded to, States across the Country are facing significant budget deficits. NASTAD has surveyed the State HIV programs and found that over half of the 36 States responding have received cuts in their State funding and staff for their programs. The anticipated cuts in State fiscal year 2010 HIV programs funding totals over \$87,000,000.

People living with HIV need access to trained HIV clinicians, life-saving and life-sustaining therapies and a full range of support services to live healthy lives and to ensure adherence to complicated treatment regimens.

All State Ryan White Part B Base and AIDS Drug Assistance Programs or ADAPs have reported to NASTAD that we are all seeing a significant and in some cases a doubling of new clients seeking HIV care and support services. This is certainly due to a number of factors including an increase in HIV testing efforts and also increasing unemployment. The continuing increase in clients and cuts to State contribution to AIDS Drug Assistance Programs certainly puts the fiscal future of ADAPs on very uncertain ground.

We respectfully request a minimum increase of \$362,000,000 for State Ryan White Part B Grants which includes an increase of at least \$113,000,000 for the Part B Base and at least \$269,000,000 for ADAPs.

NASTAD also supports a \$200,000,000 increase for a total of \$610,000,000 for the Minority AIDS Initiative which assists us in addressing health disparities further.

Turning from care to prevention, our Nation's efforts to prevent HIV must be ramped up. Every 9.5 minutes, someone in the United States is infected with HIV.

Investing in prevention is cost effective. CDC estimates that every year there are over 56,000 new HIV infections which result in approximately \$9,500,000,000 in treatment costs.

Unfortunately, over the past 5 years, CDC funding to State and local health department prevention cooperative agreements has decreased by \$21,000,000. Additionally, core HIV surveillance funding has also eroded over the last decade.

While the importance of this data has become paramount for targeting prevention efforts and directing Ryan White resources, CDC has identified the need for a funding increase of \$878,000,000 for a total funding of \$1,600,000,000 for HIV prevention.

NASTAD would respectfully request at least an initial increase of \$249,000,000 in State and local health department HIV prevention and cooperative surveillance agreements.

In addition to testing efforts and additional HIV prevention resources, State HIV programs need resources and flexibility to utilize a range of public health strategies to reduce transmission. We urge the Subcommittee not to include language banning the use of Federal funds for syringe exchange programs in the fiscal year 2010 Labor, HHS Appropriation Bill.

We also urge you to eliminate funds for the three separate Federal abstinence only until marriage programs and, instead, create a dedicated Federal funding stream of at least \$50,000,000 to fund medically accurate, comprehensive sex education programs.

We certainly also, as representatives for adult hepatitis, would urge the Committee to increase funding for the Division for Viral Hepatitis at CDC, and, lastly, we would encourage you to increase funding for sexually transmitted disease prevention, treatment and surveillance activities with the State and local health departments.

Thank you.

[The information follows:]



**Maryland Department of  
Health and Mental Hygiene  
AIDS Administration**



Testimony Submitted by

Heather Hauck, MSW, LICSW  
Director  
AIDS Administration  
Maryland Department of Health and Mental Hygiene  
and  
Chair-Elect  
National Alliance of State and Territorial AIDS Directors

Presented to the House Appropriations Subcommittee on Labor, Health and  
Human Services, and Education

On the Fiscal Year 2010 budget including:  
Centers for Disease Control and Prevention's HIV/AIDS, Viral Hepatitis and STD  
prevention programs and 317 Vaccine Program;  
Health Resources and Services Administration's Ryan White Program Part B; and  
the multi-agency Minority AIDS Initiative

Wednesday, March 18, 2009, 2:00 p.m.

As the Director of the Maryland AIDS Administration and the incoming Chair of the National Alliance of State and Territorial AIDS Directors (NASTAD), I respectfully submit testimony for the record regarding federal funding for domestic HIV/AIDS, viral hepatitis, and STD programs in the FY2010 Labor, HHS and Education Appropriations legislation. State AIDS directors appreciate the longstanding support of the House Appropriations Committee for these important public health programs.

I have the privilege of having administered state public health HIV programs for both a high prevalence state – Maryland – and a low prevalence state – New Hampshire. Therefore, I have an understanding of the resource needs of small and large state AIDS programs. The mission of the Maryland AIDS Administration is to reduce HIV transmission in our state and to help Marylanders with HIV live longer and healthier lives. The Maryland AIDS Administration administers Maryland's HIV/AIDS prevention, surveillance, and care programs, which are funded by federal and state funds.

In this testimony, I will describe the funding needs of state governmental public health HIV/AIDS, viral hepatitis, and STD programs. State public health agencies serve an essential and unique role in the delivery of HIV/AIDS prevention and care and treatment programs. The agencies are entrusted through U.S. law as the “central authorities of the nation’s public health system” and as such, bear the primary public sector responsibility for health. State public health responsibilities include disease surveillance; epidemiology and prevention; provisions of primary health care services for the uninsured and indigent; and overall planning, coordination, administration, and fiscal management of public health services.

As you craft the FY2010 Labor-HHS-Education Appropriations legislation, we urge you to consider the following critical funding needs of HIV/AIDS, viral hepatitis, and STD programs:

- \$1.6 billion for the Ryan White Part B Program, including \$514 million for the Part B Base and \$1.1 billion for the AIDS Drug Assistance Program (ADAP);
- \$1.6 billion for CDC’s HIV/AIDS Prevention Program, including an additional \$249 million for state and local health department prevention cooperative agreements to include an additional \$49 million for state and local HIV/AIDS surveillance systems, and the expansion of the Domestic HIV/AIDS Testing Initiative to additional populations and jurisdictions;
- \$50 million for CDC’s Viral Hepatitis Prevention Program, including a doubling of resources for the Adult Viral Hepatitis Prevention Coordinator Program to \$10 million.
- \$16 million for hepatitis B vaccination for high-risk adults through the Section 317 Vaccine Program;
- \$451 million for CDC’s STD Prevention Program for prevention, treatment and surveillance cooperative agreements with state and local health departments; and
- \$610 million for the Minority AIDS Initiative to enhance capacity in communities of color.

#### Need for Federal Funding

States across the country are facing significant budget deficits. The Center for Budget and Policy Priorities has said that 46 states are currently facing budget shortfalls and that 26 states have made or are proposing cuts to their public health programs. NASTAD surveyed state AIDS programs and found that over half of the 36 states responding have received cuts in their state

funding for their programs. The anticipated cuts in state FY2010 AIDS program funding totals over \$87 million for the states responding. The Maryland Department of Health and Mental Hygiene has been cut by \$121 million in state FY2009. State cuts to Maryland's STD program have resulted in a 50 percent reduction in Chlamydia screening, while we have the thirteenth highest rates in the country. Therefore, it is critical that the federal government increase its commitment to state HIV/AIDS, viral hepatitis, and STD public health programs.

In addition to program funding cuts, states are experiencing a loss in public health capacity due to reductions in staff positions, freezes in the hiring of new staff, and elimination of vacant positions. Many states have also instituted furloughs and early retirement programs. Within the 36 states responding to NASTAD's survey, there are 263 unfilled positions within state AIDS programs and 138 positions cut in HIV/AIDS and viral hepatitis programs. In Maryland, we've lost 383 positions in the health department, some of which are HIV/AIDS positions and limit our capacity to monitor and evaluate our activities.

#### HIV/AIDS Care and Treatment Programs

The Health Resources and Services Administration (HRSA) administers the \$2.2 billion Ryan White Program that providing health and support services to over 500,000 HIV-positive individuals. NASTAD respectfully requests a minimum increase of **\$362 million** in FY2010 for state Ryan White Part B grants, including an increase of at least **\$113 million** for the Part B Base and at least **\$269 million** for AIDS Drug Assistance Programs (ADAPs). With these funds all states and territories provide care, treatment and support services to persons living with HIV/AIDS. People living with HIV need access to trained HIV clinicians, life-saving and life-extending therapies, and a full range of support services to live as healthy a life as possible and to ensure adherence to complicated treatment regimens. All states are reporting to NASTAD that they are seeing a significant increase in the number of individuals seeking Part B Base and ADAP services -- for some states it's a doubling of new clients per month from the previous year. This is due to a number of factors including, increased testing efforts and unemployment.

Ryan White Part B Base programs include ambulatory medical services, case management, laboratory services, and an array of support services. As of October 10, 2008, four states report that 266 individuals are on either a medical or support service waiting list for services that include housing, mental health counseling, specialty medical care, and transportation. Five states report that funding is insufficient to ensure that all eligible patients attend medical appointments every three months, which is the standard of care. Eight Part B programs are also considering cost containment measures for their Part B services in light of high demand and reduced funding.

State ADAPs provide medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid. While only three states currently have a waiting list with 53 individuals, the present fiscal condition of state ADAPs remain fragile. In FY2008, state ADAPs were relatively stable due to increased state contributions, increased rebates from drug companies, \$39.7 million in ADAP Supplemental grants, transfers of Part B Base funding into ADAP, and program savings from the Medicare Part D Prescription Drug Benefit. The continuing increase in clients and the cuts in state contributions to ADAP (one state has cut their ADAP contribution by \$70 million) render the fiscal future of ADAPs uncertain. On average, state spending accounts for 21 percent of the total ADAP budget. Additionally, the

Centers for Disease Control and Prevention (CDC) estimates that their on-going Domestic HIV/AIDS Testing Initiative will find 20,000 new infections over the next year.

While we are very supportive of the funding increases in recent years for the community health center (CHC) program, we want to be clear that this hasn't necessarily translated into more care for person living with HIV/AIDS. CHCs focus on primary care with most of the HIV/AIDS care being provided in centers with Ryan White Part C grants.

#### HIV/AIDS Prevention and Surveillance Programs

At the request of Congress, the CDC developed a Professional Judgment Budget detailing the needed resources to significantly reduce the number of Americans becoming infected with HIV each year. CDC identified the need for a funding increase of **\$878 million** for total funding of **\$1.6 billion** for CDC's HIV prevention program in FY2010. As Congress strives to reach the \$1.6 billion overall investment in HIV prevention, NASTAD respectfully requests an initial increase of **\$249 million** in state and local health department HIV prevention and surveillance cooperative agreements. This would include an additional **\$49 million** for state and local HIV/AIDS surveillance systems and the expansion of the Domestic HIV/AIDS Testing Initiative to additional populations and jurisdictions.

An estimated 56,300 new infections occur every year while state and local HIV prevention cooperative agreements have been cut by \$21 million between FY2003 and FY2008. CDC's 2007 surveillance reports showed a 15 percent increase in HIV diagnoses in the 34 states included in the national database while CDC's HIV prevention funding was cut in FY2008 and flat-funded in FY2009. Additionally, core HIV/AIDS surveillance funding has eroded over the last decade, while the importance of this data has become paramount for targeting prevention efforts and directing Ryan White resources.

The nation's prevention efforts must match our commitment to the care and treatment of infected individuals. State and local public health departments know what to do to prevent new infections, they just need the resources. First and foremost we must address the devastating impact on racial and ethnic minority communities. We must expand outreach and HIV testing efforts targeting high-risk populations including gay and bisexual men of all races, racial and ethnic minority communities, substance users, women and youth. But, testing alone can never end the epidemic. All tools in the prevention arsenal must be supported. Additional resources must be directed to build capacity and provide technical assistance to enable community-based organizations and health care providers to implement evidence-based behavior change interventions, ensure fiscal responsibility and refer partners of HIV-positive individuals to counseling and testing services.

The Domestic HIV/AIDS Testing Initiative is an important step to increasing knowledge of serostatus, particularly among African Americans. Currently 25 jurisdictions (20 states and five cities) receive \$36 million for the Expanded Testing Initiative (ETI), including rapid testing, in clinical settings such as emergency rooms, community health centers, correctional health facilities, and STD and tuberculosis clinics. Both CDC and NASTAD conducted assessments of year-one including progress and challenges faced. Following significant scale-up efforts in all jurisdictions, 21 of the funded jurisdictions conducted 446,503 tests in year one of the ETI.



Nearly 4,000 new HIV infections were identified, 80 percent of which were in clinical settings. During the first year, 86 percent of testing occurred in clinical settings. Of the total number of tests conducted in the first year, 64 percent were administered to African Americans. Seventy percent of the newly identified infections were among African Americans.

We are requesting that CDC receive sufficient resources to expand the number of jurisdictions participating in the initiative – all jurisdictions have a need for increased resources for testing if we are to truly commit to providing access to testing for all individuals who do not yet know their HIV status. Additional funding would also allow the targeting of additional populations such as gay and bisexual men of all races and Latinos. Another key component of the initiative to expand is identification, notification and counseling of partners of persons living with HIV/AIDS. Partner services are time and resource intensive but maximize prevention efforts. With twenty-one percent of HIV-infected persons unaware that they have HIV, increased funding for testing and partner services will avert millions in unnecessary health care costs.

We urge the Subcommittee to not include language banning use of federal funds for syringe exchange programs in the FY2010 Labor-HHS Appropriations bill. Abundant research, endorsed by the findings of eight federally commissioned reviews, has conclusively demonstrated that syringe exchange is effective in reducing the transmission of HIV without increasing drug use. In communities that fund and support access to sterile injection equipment using state and local funds, transmission of HIV and hepatitis in persons who inject drugs has declined as a proportion of all cases by mode of transmission. Unfortunately, state and locally funded syringe exchange are only reaching a small portion of persons who inject drugs. It's time for the federal government to use every tool at its disposal to arrest the further spread of HIV and hepatitis C.

We also urge you to eliminate funds for the three separate federal abstinence-only-until-marriage programs. Instead, we request that you create a dedicated federal funding stream of at least \$50 million in your 2010 budget to fund medically accurate, comprehensive sex education programs that teach young people about both abstinence and contraception.

Lastly, we thank you and ask that you continue to limit the funding for the duplicative Early Diagnosis Grant Program in Section 209 of the *Ryan White Treatment Modernization Act of 2006*. This program is a carve out of limited HIV testing resources when there is already \$10 million dedicated to perinatal prevention.

#### Viral Hepatitis Prevention Programs

NASTAD respectfully requests an increase of \$36.4 million for a total of **\$50 million** in FY2010 for the CDC's Division of Viral Hepatitis (DVH) to enable state and local health departments to provide basic core public health services. DVH currently receives \$18.3 million to address chronic viral hepatitis B and C impacting 6.2 million Americans. This is \$7 million less than its peak funding of \$25 million in FY2001. Currently CDC addresses viral hepatitis on outbreak at a time, which is neither cost-effective nor real prevention.

Of the DVH funding, \$5.2 million is used to fund the Adult Viral Hepatitis Coordinator Program with an average award to states of \$90,000. Doubling this program to \$10 million would allow

states to implement a hepatitis prevention strategy. The coordinator position receives precious little above personnel costs, leaving little to no money for the provision of public health services including public education, hepatitis counseling, testing, and hepatitis A and B vaccine. In addition, there are no funds for surveillance of chronic viral hepatitis, which would allow states to better target their limited resources. Given the recent hepatitis public health crises in Nevada and New York, the government has a choice - invest in prevention now or wait until public systems are overwhelmed by a lack of infrastructure to address future outbreaks.

The greatest remaining challenge for hepatitis A and B prevention is the vaccination of high-risk adults. High-risk adults account for more than 75 percent of all new cases of hepatitis B infection each year and annually result in an estimated \$658 million in medical costs and lost wages. In FY2007, CDC allowed states to use \$20 million of 317 Vaccine funds to vaccinate high risk adults for hepatitis B and \$16 million in FY2008. By targeting high-risk adults, including those with hepatitis C, for vaccination, the gap between children and adults who have not benefited from routine childhood immunization programs can be bridged. NASTAD requests a continuation of the **\$16 million** in Section 317 Vaccine funds in FY2010 for hepatitis B vaccination for high-risk adults with the request that in the future DVH receives dedicated funding for hepatitis A and B vaccine for high risk adults and funding to support the infrastructure necessary for vaccine delivery.

#### STD Prevention Programs

NASTAD supports an increase of **\$299 million** for a total of \$451 million in FY2010 for STD prevention, treatment and surveillance activities undertaken by state and local health departments. STD prevention programs at CDC have been cut by \$6 million since FY2004 while the number of persons infected continues to climb. The U.S. has the unwanted distinction of having the highest rates of STDs of all industrial nations with one in four adolescent girls in the U.S., or more than 3 million, having an STD. The rates of syphilis infection have increased for the seventh year in a row. In one year, our nation spends over \$8 billion to treat the symptoms and consequences of STDs. Additional federal resources are needed to reverse these alarming trends and reduce the nation's health spending.

#### Minority AIDS Initiative

NASTAD also supports a **\$200 million** increase for a total of \$610 million for the Minority AIDS Initiative (MAI) in FY2010. The MAI provides targeted resources to four agencies and the Office of the Secretary to address the HIV/AIDS epidemic in hard-hit communities of color. The data from CDC on the disproportionate impact on African Americans and Latinos continues to be alarming. Support for the MAI along with the traditional funding streams that serve these populations is essential.

As you craft the FY2010 Labor, HHS and Education Appropriations bill, we ask that you consider all of these critical funding needs. The Maryland AIDS Administration and the National Alliance of State and Territorial AIDS Directors thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV, viral hepatitis and STD epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's fight against these infectious and often chronic diseases.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

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93.940	HIV Prevention Cooperative Agreement and Expanded Testing Grant (CDC)	\$9,935,894	\$9,549,047	\$11,735,724																																																											
93.941	Enhanced Perinatal Surveillance and Prevention (CDC)	\$122,734	\$127,687	\$135,870																																																											
93.944	HIV/AIDS Surveillance Program (CDC)	\$1,882,819	\$1,911,435	\$1,564,759																																																											
93.959	Block Grants for Prevention and Treatment of Substance Abuse (SAMHSA)	<u>\$585,950</u>	<u>\$420,714</u>	<u>\$425,930</u>																																																											
		\$53,656,248	\$51,164,743	\$51,440,355																																																											
CDC Grant Number U62/CCU323958	\$3,235,908																																																														
CDC Grant Number U62/CCU324956	7,203,000																																																														
CDC RFA P508-862	\$150,000																																																														
CDC PA 03099	\$150,000																																																														
HRSA Grant Number U69HA10604	\$370,000																																																														
HRSA Grant Number U69HA05543	<u>\$600,000</u>																																																														
	\$11,708,908																																																														
Signature: <i>Heather Hauck</i> Date: 3/16/09																																																															

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

**Heather Hauck, MSW, LICSW**  
**2009 Biography**

Heather Hauck is the Director of the Maryland Department of Health and Mental Hygiene AIDS Administration. The Maryland AIDS Administration leads statewide public health efforts to reduce HIV transmission in Maryland and to help Marylanders with HIV/AIDS live longer and healthier lives. The Maryland AIDS Administration accomplishes its mission by working with public and private partners to develop and implement comprehensive, compassionate, and high quality services for both prevention and care.

Ms. Hauck is currently the Chair-Elect of the National Alliance of State and Territorial AIDS Directors (NASTAD) and has been a member of the organization since 2003. She serves on NASTAD's Executive Committee, Membership Committee, and the NASTAD Global Program Ethiopia team.

Prior to joining the Maryland AIDS Administration, Ms. Hauck was an independent consultant providing technical assistance to hospitals, national associations, and state public health agencies on HIV program development issues. She served as the Section Chief of the New Hampshire DHHS Division of Public Health STD/HIV Section in Concord, NH from 2003 to 2006. Prior to her work in New Hampshire, Ms. Hauck was a co-director and a social worker in the Washington Hospital Center Social Work Department in Washington, D.C. Ms. Hauck began her work in HIV in 1992 with the Coalition of Labor Union Women providing training and education materials on HIV and women. She has a Master of Social Work degree from the National Catholic School of Social Service, Catholic University of America in Washington, D.C.

Mr. OBEY. Thank you.

We have a dilemma. We have three people left on the sheet, and with the number of votes that are occurring it could be as much as an hour before we get back here. So I am going to ask you what you want to do.

We can either give each of you the opportunity to summarize your statement in about a minute, so that everybody gets a chance to say something, or we can ask that you simply hold it until we get back in about an hour. What is your choice?

Mr. WRIGHT. I will take a minute.

Mr. OBEY. All right. Grab the mic.

You are David Wright?

Mr. WRIGHT. David Wright, yes, sir.

Mr. OBEY. Do we have Charmaine Ruddock and Robert Pestronk in the room?

Ms. RUDDOCK. Yes.

Mr. OBEY. What are your choices?

Mr. PESTRONK. I will do it in a minute.

Mr. OBEY. Okay.

Ms. RUDDOCK. I will as well.

Mr. OBEY. All right. Let's try to do it in one minute.

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WEDNESDAY, MARCH 18, 2009.

## **ALLIANCE FOR BIOSECURITY**

### **WITNESS**

#### **DAVID P. WRIGHT**

Mr. WRIGHT. Thank you very much, Mr. Chairman and members of the Subcommittee.

I am here today on behalf of the Alliance for Biosecurity. The Alliance is a consortium that includes the Center for Biosecurity from the University of Pittsburgh and about 13 biopharmaceutical companies.

The Alliance is here today to request that the Subcommittee provide \$1,700,000,000 in their fiscal year 2010 appropriation for BARDA specifically to support advanced development of medical countermeasures against bioterrorism.

This is a large amount of money. However, bioterrorism is real. In the recent report by the bipartisan Commission on the Prevention of Weapons of Mass Destruction, it was predicted that in 2013 a weapon of mass destruction is most likely to be used during that time and will be a biological agent.

We need to support biodefense and in a way that is consistent with the way we support our troops. This is very much needed, and I look forward for an opportunity to talk to you about this in the future.

Thank you.

[The information follows:]

## Alliance for Biosecurity

Office of the Secretary and Legal Counsel  
1500 K Street, NW, Suite 1100  
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### COVER PAGE

**Written Testimony Submitted to the House of Representatives  
Labor, Health and Human Services, and Education Appropriations Subcommittee  
Regarding FY 2010 Funding for BARDA Advanced Research and Development**

**Submitted by:**

David P. Wright,  
Co-Chair of the Alliance for Biosecurity, Washington, DC  
[david.wright@pharmathene.com](mailto:david.wright@pharmathene.com)  
410 269-2500

**March 18, 2009  
2 pm**

### Summary

The Alliance for Biosecurity respectfully requests that the Subcommittee provide \$1.7 billion in FY 2010 in the Public Health and Social Services Emergency Fund for medical countermeasure advanced research and development. This would allow the Biomedical Advanced Research and Development Authority (BARDA) within the Department of Health and Human Services (HHS) to effectively support development of drugs, vaccines and other medical countermeasures needed to protect Americans from bioterrorism and other catastrophic health emergencies.

Bioterrorism and emerging infectious diseases present an extraordinary and potentially grave threat to public health and national security. One of the most effective ways to improve our national preparedness for these threats is through the development of medical countermeasures that can be distributed in the event of an emergency. The federal government has a central role to play in developing these medical countermeasures, and in BARDA it has an effective tool for doing so. We very much appreciate the Subcommittee's consideration of our views, and we stand ready to work with Subcommittee members and staff on this and other biosecurity matters.

**Investing in Innovation to Strengthen Biosecurity, Create Jobs, & Advance Drug Development**

Biosecurity is a Critical National Security Challenge

The Alliance for Biosecurity appreciates the opportunity to submit written testimony to the House Labor, Health and Human Services, and Education Appropriations Subcommittee. The Alliance is a collaboration between the Center for Biosecurity of the University of Pittsburgh Medical Center (UPMC) and biopharmaceutical companies working to develop vaccines and medicines for our nation's civilian Strategic National Stockpile (SNS) and the US military. The Alliance mission is to work in the public interest to promote a robust and sustainable research and development infrastructure necessary to prevent and treat chemical, biological, radiological, and nuclear (CBRN) threats as well as infectious diseases that present security challenges in the 21st Century. To ensure that we have the funds necessary to develop safe and effective countermeasures, the Alliance requests that the Subcommittee consider providing \$1.7 billion in 2010 for the Biomedical Advanced Research and Development Authority (BARDA).

The United States is engaged in an important national security effort to support the development and manufacture of new drugs, vaccines, and diagnostic tests needed to protect Americans from CBRN and emerging infectious disease threats. Currently, medical countermeasures for many of the agents of greatest concern do not exist. Until these medical countermeasures are developed, manufactured and stockpiled, our country will remain vulnerable to terrorist attacks.

The December, 2008 report of the Congressionally established *Commission on the Prevention of Weapons of Mass Destruction Proliferation and Terrorism* found that "it is more likely than not that a weapon of mass destruction will be used in a terrorist attack somewhere in the world by the end of 2013," and that "terrorists are more likely to be able to obtain and use a biological weapon than a nuclear weapon." Along similar lines, in November of 2008 the National Intelligence Council reported that "one of [its] greatest concerns continues to be that a terrorist might acquire and employ biological agents, or less likely, a nuclear device, to create mass casualties."<sup>1</sup>

These findings reflect the fact that bioterrorism represents one of the direst threats to national security. Bioterrorism is on par with nuclear terrorism in terms of lethality, but far more likely given the lower technological thresholds to create and deploy a biological agent. Medical countermeasures must be created in order to reduce our vulnerability to this very real threat. For now, however, the United States remains vulnerable to biological threats, both because (1) many of the medical countermeasures that the US has identified as essential to procure have not yet completed development; and (2) the potential list of biological threats is growing, driven by the ongoing revolution in the life-

sciences that opens doors to the development of new and potent bioengineered threats. Addressing threats posed by known and unknown bioterror pathogens, pandemic influenza, and other destabilizing emerging infectious diseases requires sustained investment and creative partnerships between government, industry, and other stakeholders. Already, there have been extraordinary advances achieved through government investment and partnership with industry with respect to preparedness for pandemic influenza. A similar collective endeavor is not only critical to biosecurity, but it also presents opportunities to leverage cutting edge innovation in the biodefense space to advance and rapidly accelerate drug development for a broad range of emerging infectious diseases in the US and around the world.

#### Government Resources

New drug development is an extraordinarily time and resource-intensive process that, on average, requires 10-15 years and approximately \$800 million from start to finish for one product<sup>ii</sup>. Development is also high-risk: 80% of all candidates that enter clinical trial fail to attain FDA approval. This process is especially complicated in the case of medical countermeasures, due to a number of factors including the ethical impossibility of human efficacy trials in many cases, the lack of established animal models, and the uncertainty surrounding the FDA animal efficacy rule. Most importantly, because many of these products have either a limited commercial market or no commercial market whatsoever, raising private capital for product research and development is extremely difficult, and often impossible.

Congress has recognized some of these challenges and addressed them by creating effective tools to meet the nation's biosecurity needs, including Project BioShield and BARDA within HHS. Project BioShield is a federal program established in 2004, which provided special authorities to HHS to allow the *procurement and stockpiling* of medical countermeasures against the CBRN agents. Congress provided Project BioShield with a \$5.6 billion appropriation through FY 2013 for this purpose, an adequate initial level given current medical countermeasure availability. However, fully furnishing the SNS will eventually require additional funds, particularly if the existing appropriation is drawn down to fund other priorities. Several critical medical countermeasures, including those for use against anthrax, radiological and nuclear agents, and botulinum toxin, have already been acquired with Project BioShield funds. But as of the midway point of FY 2009, \$3.7 billion of the BioShield appropriation remains unobligated. This is because only a few countermeasures are advanced enough for procurement. Many of those that are in the later stages of development are stalled due to lack of government funding. Developing countermeasures requires a partnership with the government, because in most cases the government is the only customer and the markets are small. Consequently, it is often not possible for companies to attract and sustain the private investments required to fund a company's R&D for the many years of work required before BioShield procurement becomes possible. This is, unfortunately, not simply an academic problem: the development risk attached to creating medical countermeasures has already begun to undermine the goals of Project BioShield.



BARDA was established in 2006 through the Pandemic and All-Hazards Preparedness Act (PAHPA) to address this problem. BARDA leads and coordinates MCM initiatives across the federal government and was set up to provide advanced development funding for promising medical countermeasures. Specifically, BARDA bridges the funding gap between early-stage research and the ultimate procurement of products for the national stockpile under Project BioShield. Early-stage research is often supported by the National Institutes of Health (NIH), and for this reason the Alliance supports robust funding for NIH and the National Institute for Allergy and Infectious Diseases, which perform much of the basic biomedical research critical to the development of medical countermeasures. The gap between this early-stage research and BioShield procurement – often referred to as the “Valley of Death” – is where many promising technologies and products have languished as the result of scarce resources. By partnering with private industry and providing financial support, BARDA can reduce the development risk entailed in medical countermeasure research, thereby helping to mitigate the disincentives associated with countermeasure development, and ultimately improving our national readiness posture with regard to a chemical, biological, radiological or nuclear attack.

BARDA is ready to effectively deploy the \$1.7 billion we are recommending for FY 2010. It has already made significant advances despite more limited funding, particularly since coming under the successful leadership of Director Robin Robinson in the spring of 2008. Dr. Robinson previously ran HHS’s highly successful pandemic influenza medical countermeasure program and exhibited a superb ability to partner with the private sector and manage complex drug development programs. The Alliance views Dr. Robinson as an able administrator and manager, and a strong leader in the field of public health preparedness and drug development. As Director, Dr. Robinson has described a vision of using BARDA’s investments in medical countermeasures for CBRN threats to improve overall development of drugs and vaccines for influenza and emerging infectious diseases. After an initial ramp-up period, BARDA has begun to move aggressively to fulfill its mandate. BARDA has brought in over 200 expert personnel, and in September of 2008 alone it awarded seven contracts to advance the development of products to treat patients with heavy radiation exposure. In the period since its creation in December of 2006, BARDA has awarded contracts to support the advanced development of vaccines for Ebola and Marburg hemorrhagic fevers, antibiotics for plague and tularemia, and an immunoglobulin and a range of antitoxins for the treatment of anthrax.

BARDA is an effective, agile organization that appreciates the urgency of the challenge it confronts, and is making significant contributions to the development of new medical countermeasures against CBRN threats, pandemic influenza, and emerging infectious diseases. There is now an enormous opportunity to leverage BARDA’s largely untapped potential. A level of BARDA funding more reflective of the magnitude of the threat of CBRN terrorism and emerging infectious disease would improve our nation’s security against weapons of mass destruction, stimulate the biotech sector, drive biomedical science forward, and ensure our country’s continued global leadership in this critical field. Increased funding would also take advantage of BARDA’s potential as an engine of innovation to support development of new science, technology platforms, and

accelerated development processes that could be applied to a range of medicines and vaccines against infectious diseases.

Requested BARDA funding level

BARDA was initially authorized at \$1.07 billion over three years, and Congress has provided \$476 million for BARDA since its creation in December 2006. The Subcommittee is to be commended for its efforts to improve our nation's preparedness by dedicating resources to this critical program, and the Alliance is deeply appreciative of the Subcommittee's support for this national security priority. We also thank the Subcommittee for its efforts to include substantial funding for BARDA in the American Recovery and Reinvestment Act of 2009.

However, available data suggests that increased BARDA funding could significantly expedite medical countermeasure development. A recent independent analysis by the Center for Biosecurity<sup>iii</sup> estimated that \$14 billion through FY 2015 in advanced development funding for BARDA would be required to have a 90% chance of ultimately developing just one successful medical countermeasure for each of the eight biodefense requirements set forth in HHS's PHEMCE Implementation Plan<sup>iv</sup>. Increased funding would advance the day when our nation has access to these countermeasures; until that day arrives, the American people remain vulnerable.

Furthermore, we note that a funding increase would have an immediate and significant stimulative impact on the biodefense industry, as well as on the US economy. Biotech firms, were they to receive increased BARDA funds in FY 2010, could immediately begin putting these resources to work. The U.S. Bureau of Economic Analysis estimates that each new biotech job results in the creation of 5.8 additional jobs in other industries. For every dollar of labor earnings or output in the biotech sector, another \$2.90 or \$1.70, respectively, are produced in other parts of the economy.

Finally, it is important to understand that a sustained effort by industry and government to produce vaccines and therapeutics for the strategic national stockpile will only be possible with a long-term commitment to funding by the federal government. The nation's biodefense procurement goals will not be achieved with a one-year appropriation. A sustained level of funding is necessary for the US to have a reasonable chance of meeting its stated commitment to national biosecurity.

To address our nation's ongoing vulnerability and to provide needed economic stimulus, we urge you to consider funding BARDA at \$1.7 billion in FY 2010. We recognize that FY 2010 may prove to be an austere fiscal environment given the current economic situation and associated federal spending. But developing new medical countermeasures, while expensive in health budget terms, is dwarfed by traditional national security budgets. Investment in BARDA will enable it to improve our national security and benefit research and development with broader application to emerging infectious diseases. Without sufficient funds, promising products will languish and the nation will remain vulnerable.

We thank you for your consideration, and we look forward to working with you and the Subcommittee to increase our country's preparedness against biological weapons.

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<sup>i</sup> *Global Trends 2025: A Transformed World* (NIC 2008-003). Washington, DC: National Intelligence Council. November 2008

[http://www.dni.gov/nic/PDF\\_2025/2025\\_Global\\_Trends\\_Final\\_Report.pdf](http://www.dni.gov/nic/PDF_2025/2025_Global_Trends_Final_Report.pdf). Accessed February 10, 2009.

<sup>ii</sup> DiMasi, J.A. et al, 2003. The Price of Innovation: New Estimates of Drug Development Costs. *Journal of Health Economics* 22, 151–185.

<sup>iii</sup> Matheny, J., Mair, M., and Smith, B. T. 2008. Cost/Success Projections for US Biodefense Countermeasure Development. *Nature Biotechnology*. 26:981-983.

<sup>iv</sup> PHEMCE is the Department of Health and Human Services' Public Health Emergency Medical Countermeasure Enterprise Implementation Plan for Chemical, Radiological and Nuclear Threats.

Oral Testimony  
Of  
David P. Wright  
Co-Chair Alliance for Biosecurity  
Before the  
House Committee on Appropriations, Subcommittee on Labor, Health & Human  
Services, Education, and Related Agencies

March 18, 2009

Mr. Chairman, Members of the Subcommittee: I welcome the opportunity to testify before you today on behalf of the Alliance for Biosecurity on the critical need for adequate funding for the development of CBRN countermeasures in the Fiscal Year 2010 budget.

I am David Wright, Co-chair of the Alliance for Biosecurity and President and Chief Executive Officer of PharmAthene. PharmAthene is a biotechnology company specializing in the development and commercialization of biological and chemical defense countermeasures. The Alliance for Biosecurity is a consortium that includes the Center for Biosecurity of the University of Pittsburgh Medical Center and 13 biopharmaceutical companies.

The Alliance is here today to request that the Subcommittee provide \$1.7 billion in the FY 2010 appropriation for the Biomedical Advanced Research and Development Authority –BARDA, specifically to support advanced research and development of medical countermeasures. Protecting our nation against bioterror threats is no less important than ensuring that we have the tools necessary to fortify and protect our military. However, funding for the development of CBRN countermeasures, particularly in the area of advanced development – often referred to as the “Valley of Death” – has been woefully inadequate. Without adequate funding, promising countermeasures will not be developed and the nation will remain vulnerable to a bioterror attack – and make no mistake a bioterror attack is a real and credible threat. The recent report by the bipartisan *Commission on the Prevention of Weapons of Mass Destruction Proliferation and Terrorism* predicted a terror attack somewhere in the world by 2013 using a weapon of mass destruction, most likely a biological agent.

Promising countermeasures do exist. For example, Alliance companies are developing new vaccines and therapies to combat anthrax, botulism and plague. Several of our companies have already delivered important anthrax and smallpox countermeasures to the country's Strategic National Stockpile, but most countermeasure products are in the early stages of development. The core group of companies in the biodefense space is small and the number of procurable products few. New drug development is a time consuming and resource-intensive process that requires 10-15 years and approximately \$800 million from start to finish for just one product<sup>i</sup>. Adequate funding will both expand the pool of companies developing biodefense products and the number of promising products available to protect the American people.

It will also increase job creation. The U.S. Bureau of Economic Analysis estimates that each new biotech job results in the creation of 5.8 additional jobs in other industries. For every dollar of labor earnings in the biotech sector, another \$2.90 is produced in other parts of the economy.

Developing new medical countermeasures, while expensive in health budget terms, is dwarfed by traditional national security budgets. Sustained investment in BARDA is required to improve our national security and benefit research and development with broader application to emerging infectious diseases. A one year fix will not achieve our long-term goal of national biosecurity.

Before I close my remarks, I would like to take a moment to acknowledge and thank Chairman Obey and the Subcommittee for your commitment to biodefense. We appreciate the funding included in the FY 2009 HHS appropriation for BARDA and your efforts to include substantial funding for BARDA in the American Recovery and Reinvestment Act of 2009.

We thank you for your consideration, and we look forward to working with you and the subcommittee to increase our country's preparedness against biological weapons and other biosecurity threats.

<sup>i</sup> DiMasi, J.A. et al, 2003. The Price of Innovation: New Estimates of Drug Development Costs. *Journal of Health Economics* 22, 151–185

**David P. Wright**  
**President & Chief Executive Officer**

Mr. Wright joined PharmAthene as President and Chief Executive Officer in July 2003. Prior to joining PharmAthene, Inc he served as President and Chief Operating Officer of GenVec Inc, and previously President and Chief Business Officer of Guilford Pharmaceuticals. Mr. Wright served as Executive Vice President for MedImmune, Inc from 1990 to 2000 where he was responsible for building MedImmune's commercial operation and growing product sales from \$0 to over \$400 million per year. Additionally he has held various marketing and sales positions at pharmaceutical companies including Smith-Kline & French, G.D. Searle, and Glaxo. Mr. Wright received his Master of Arts in Speech Pathology and Audiology from the University of South Florida.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number:

David Wright, President and CEO  
PharmAthene, Inc.  
One Park Place, Suite 450, Annapolis, MD 21401  
(410) 269-2600

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

Alliance for Biosecurity

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

☒ Yes    ☐ No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

PharmAthene has received the following:

Title	Source	Value
Biodefense Vaccine Enhancement	BARDA	\$83,891,328
DoD Appropriation	DoD	\$1,600,000
Development of Therapeutic Agents for Selected Biodefense Bacterial Diseases	NIH	\$13,920,347
DoD Appropriation FY07 – Evaluation of the Anti-Toxin mAB Valortim for Inhalational Anthrax	DoD	\$1,000,000
DoD Appropriation FY08 – Evaluation of the Anti-toxin mAB Valortim for Inhalational Anthrax	DoD	\$1,470,040

Signature: 

Date: 17 March 2009

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. All right. Thank you, and I apologize for cutting you short.

Next, Charmaine Ruddock.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL REACH COALITION**

**WITNESS**

**CHARMAINE RUDDOCK**

Ms. RUDDOCK. Good afternoon, Chairman Obey, Ranking Member Tiahrt and other members of this distinguished Committee.

I am Charmaine Ruddock, Project Director for the Bronx Health REACH New York program funded by the CDC. My testimony today is on behalf of the National REACH Coalition, which represents more than 40 communities and coalitions in 21 States, working to improve the health of African Americans, Asian Pacific Islander, Native American and Latino populations and communities.

Expanding funding for REACH programs provides a sound science-based approach that improves the health of these communities while also rebuilding infrastructure, creating jobs and stimulating the local economy.

In 2007, more than 200 communities applied for funding in the last CDC REACH program application cycle, but only 40 were funded. Of the 160 who applied that were unfunded, 42 alone were from States and districts from members on this Committee.

REACH communities have spent the last decade leveraging CDC funding with public-private partnerships to effectively address health disparities. Using innovative science-based approaches, we have demonstrated that health disparities, once considered expected, are not unsolvable.

Thank you.

[The information follows:]



## The National REACH Coalition

**Witness Name:** Charmaine Ruddock

**Title:** Project Director

**City, State:** Bronx, New York

**Institutional Affiliation:** REACH US Grantee, Bronx Health REACH at the Institute for Urban Family Health

**Hearing Date:** March 18, 2009

**Hearing Time:** 2:00 PM

**Organization:** National REACH Coalition

**Summary of Testimony:** I will be testifying on behalf of the National REACH Coalition, which represents the over 40 community and faith-based organizations, academic institutions and researchers in state and local health departments who work daily to eliminate racial and ethnic health disparities. REACH US programs are the cornerstones of their communities; they have been rigidly evaluated and have proven their effectiveness in decreasing health disparities in some of the nation's most underserved communities. REACH US began as the REACH 2010 initiative, a federally funded demonstration project coordinated through the Centers for Disease Control and Prevention (CDC). REACH 2010 was designed to develop and demonstrate effective strategies and community-based interventions to improve health outcomes among racial and ethnic minority communities. Today, REACH US programs work in communities across the country to provide coordination and leadership for the advancement and translation of community-based participatory research into evidenced-based practices, policies and community empowerment. REACH programs are on the front lines in fighting chronic disease and other health disparities among our racial and ethnic minority communities; when REACH programs are underfunded, so too is the health of that community. REACH US is currently funded at \$35.4 million. The current REACH US programs are using this funding to invest and grow their communities, but many more communities across the U.S do not have a REACH program. In 2007, 200 communities applied for REACH funding but only 40 were funded. Increased funding would help to fund these "ready to go" projects and would help to fight health disparities in many more communities throughout the United States.

**NATIONAL REACH COALITION  
FOR THE ELIMINATION OF HEALTH DISPARITIES**

March 18, 2009  
*Testimony By*  
Charmaine Ruddock

Good afternoon Chairman Obey, Ranking Member Tihart and other members of this distinguished Subcommittee. Thank you for the opportunity to testify before you today. I am Charmaine Ruddock, with the Institute for Family Health in New York, a family practice model network of health centers. I serve as Project Director for the Institute's Bronx Health REACH/New York CEED program funded by the CDC. I am pleased to share with you the results of a remarkable program that with limited federal dollars has shown a large return on investment.

My testimony today is on behalf of the National REACH Coalition, which represents more than 40 communities and coalitions in 22 states working to eliminate racial and ethnic health disparities and improve the health of African American, Asian Pacific Islander, Native American and Latino populations and communities. The coalition is an outgrowth of the **Racial and Ethnic Approaches to Community Health (REACH)** 2010 initiative, started a decade ago by the Centers for Disease Control and Prevention (CDC). As a REACH grantee, I've seen this unique community-based program achieve positive health outcomes in cardiovascular disease, diabetes, breast and cervical cancer, hepatitis B, adult immunization, tuberculosis, asthma and infant mortality with limited federal investment.

Today's economic crisis is severely straining our American families and communities and continues to widen the health disparities gap. Expanding funding for REACH programs

National REACH Coalition Testimony  
March 18, 2009  
Page 2 of 5

provides a sound, science-based approach that improves' the health of these communities while also rebuilding the infrastructure, creating jobs and stimulating the local economy. To put it simply, REACH programs give you the best bang for your buck.

We know that providing access to health care is only a partial answer. In our communities, health insurance does not ensure access to a quality provider, or an ability to pay for medications. Even with these items in place, community and environmental disadvantages continue to contribute to health disparities. Studies have shown Black and Latino neighborhoods have fewer parks, green spaces, gyms, recreational centers, swimming pools and safe places to walk, jog, bike or play than white neighborhoods. Nationally, 50% of African American neighborhoods lack access to a full-service grocery store or supermarket.<sup>1</sup> It's difficult to eat right in neighborhoods where fast-food outlets, liquor stores and convenience stores dominate over supermarkets or other sources of affordable, nutritious food.

Having worked with the Bronx REACH program since its inception, I can tell you first hand that health disparities are NOT intractable. The 2003 GAO report, *Health Care: Approaches to Address Racial and Ethnic Disparities* identified REACH as one of the nation's most effective programs in addressing health disparities. The data are compelling. For example:

- The rate of cigarette smoking among Asian American men in REACH communities decreased from 42% in 2002 to 20% in 2006, dipping below the national average for the overall U.S. population.
- In 8 years, the proportion of African American women who received mammography screenings increased from 29% to 61%, surpassing the rate for white women by 13%.
- Since 2002, the cholesterol screening rate for Hispanics in REACH communities has surpassed the national rates for Hispanics.

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<sup>1</sup> Flournoy, R.; "Regional Development and Physical Activity: Issues and Strategies for Promoting Health Equity," PolicyLink, Oakland, CA, November 2002, p.10

These dramatic changes are taking place in your communities and others across the United States. REACH is a time-tested 8-component model that includes the following core principles: Trust, Empowerment, Culture and History, a Focus on the Underlying Causes, Community Investment and Expertise, Trusted Organizations, Community Leadership and Ownership, Sustainability and Hope. The uniqueness of this REACH model is that we address and create a community intervention based upon that community's own assessment and response to their health problem(s). REACH programs are the cornerstones of their communities' efforts to effectively address the elimination of health disparities and promote positive health outcomes.

Here are some specific examples from some of your communities:

At my REACH site, the **Bronx Health REACH Coalition**, we have worked with more than 40 community and faith based organizations to among many things; improve residents' access to healthy foods. As a result, **New York City schools have switched from whole milk to low fat milk**, neighborhood grocers carry low-fat milk and healthier snacks, and local restaurants highlight their healthy menu options.

In Birmingham Alabama, the **REACH Breast and Cervical Cancer Coalition** launched a patient navigation program to increase screening rates for African American women throughout the state. As a result, the black/white mammography gap has been reduced by 76% across the 8-county region.

In Los Angeles California, the **Community Health Councils' *African Americans Building a Legacy of Health*** coalition has improved food and physical activity options through zoning and land use policy change. Through these efforts, the Los Angeles City Council recently adopted an ordinance to limit the proliferation of fast food restaurants while also

National REACH Coalition Testimony  
March 18, 2009  
Page 4 of 5

providing incentives to healthy food retailers to encourage them to locate in disadvantaged areas, paving the way for two new grocery stores.

In Santa Clara County, the **University of California, San Francisco Vietnamese REACH for Health Initiative Coalition** reports that 48% of Vietnamese women who had never had a Pap test got one after REACH lay health workers provided culturally appropriate health education and assisted the women with navigating their local healthcare system. The overall percentage of Vietnamese American women receiving pap tests has increased by 15%.

In Illinois, the **Chicago Department of Health, REACH/Lawndale Health Promotion Project** has conducted more than 7,000 assessments for diabetes and heart disease risk among community residents. Nine hundred residents were referred to local health agencies for medical care and 350 residents with diabetes or heart disease received case management services, which sharply increased their use of health screenings.

In Oklahoma the **Choctaw Nation Core Capacity Building Program** has successfully worked with its partners to create 12 community coalitions to raise awareness about heart disease prevention, improving access to care, and assessing the health needs of each community.

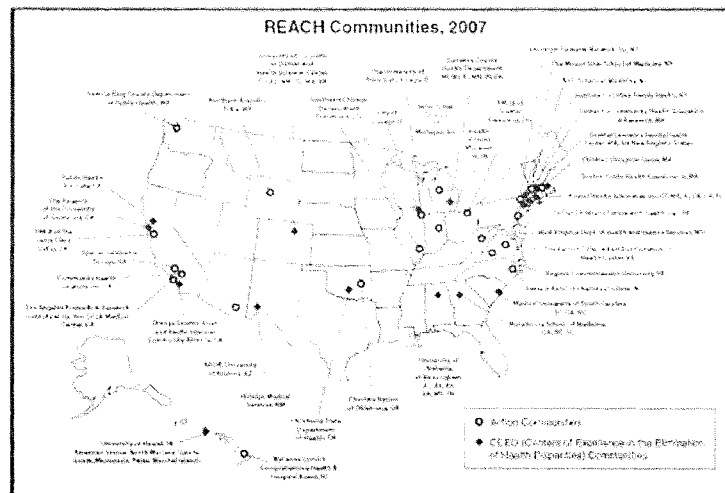
In conclusion, REACH communities have spent the last decade leveraging CDC funding with public private partnerships in order to effectively address health disparities. Using innovative science-based approaches we have demonstrated that health disparities once considered expected are not intractable. REACH has provided a sound return on investment, but we could do a lot more. In 2007, more than **200 communities** applied for funding in the last CDC REACH program application cycle, but only 40 were funded. Of the 160 who applied and were unfunded, 42 alone were from states and districts from members on this committee. As you can see on the map, there are large sections of our country where no REACH program is

National REACH Coalition Testimony  
 March 18, 2009  
 Page 5 of 5

available to address health disparities. With enhanced and sustained funding for REACH US the elimination of racial and ethnic health disparities is within our -- REACH.

Thank you for this opportunity to present this testimony. I look forward to your questions.

### Racial and Ethnic Approaches to Community Health (REACH U.S.) 2008



### States without REACH Funding

Alaska	Maryland	Oregon
Arkansas	Minnesota	Rhode Island
Delaware	Mississippi	South Dakota
Florida	Missouri	Tennessee
Idaho	Montana	Texas
Iowa	Nebraska	Utah
Kansas	Nevada	Vermont
Kentucky	New Hampshire	Wisconsin
Louisiana	New Jersey	
Maine	North Dakota	

**Charmaine Ruddock, MS**  
**Project Director, Bronx Health REACH/NY CEED**  
**The Institute for Family Health**

Charmaine Ruddock has been involved in the administration of health care services to medically underserved communities for more than 15 years, notably in the design, development, and operational oversight of Medicaid Managed Care Organizations serving communities in New York City, Long Island and Connecticut. She has sat on the Board of Directors of the New York Prenatal Care Steering Committee and HHFII, organizations dedicated to improving the health outcomes of New Yorkers. Currently, Ms. Ruddock is a member of the National REACH Coalition's Steering Committee and the National Coalition for Health Equity working on the development of a National Action Plan to address health disparity.

Ms. Ruddock joined the Institute for Family Health formerly known as The Institute for Urban Family Health in 2000 to direct Bronx Health REACH, a coalition of 40 community and faith-based organizations, funded by the Centers for Disease Control REACH 2010 Initiative. As of 2007, Ms. Ruddock now directs the Bronx Health REACH/New York Center of Excellence to Eliminate Disparity, part of the CDC's REACH US initiative (the next generation of REACH). In addition to REACH, Ms. Ruddock also directs two other diabetes-focused initiatives - the Diabetes Prevention and Control Initiative funded by the New York State Department of Health Bureau of Chronic Diseases Services and an NIH funded initiative exploring the use of faith-based organizations to provide diabetes education. Bronx Health REACH's goal is the elimination of racial and ethnic disparities in health outcomes in the New York state. The health priority focus is diabetes and heart disease. Ms. Ruddock is working with several community groups, faith-based organizations and health care providers to implement several initiatives, namely: - Primary Prevention and Public Health Education Program; Community Health Advocacy; Faith-Based Outreach efforts; a Legal and Regulatory workgroup; and, Grocer and Restaurant Outreach Program.

Ms. Ruddock holds a BA. in Literature and Social Sciences from the University of the West Indies and a Masters of Science in Management and Policy Analysis from the Graduate School of Management, The New School for Social Research.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

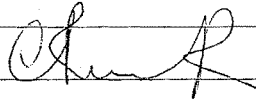
**Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.**

Your Name, Business Address, and Telephone Number: Charmaine Ruddock  Institute for Family Health 16 E. 16 <sup>th</sup> Street New York, New York 10003  212-633-0800 ext 1291	
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.  Non-governmental Agency The Institute for Family Health The National REACH Coalition	
2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?  Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.	
<b>Federal Agency and Program</b>	<b>Amount</b>
Centers for Disease Control and Prevention, Center of Excellence – REACH program	\$850,000 annually



NIH, National Center on Minority Health and Health Disparities	\$520,000 annually
NIH Collaboration to Eliminate Disparities	\$200,000
Health Resources Services Administration (HRSA), Bureau of Primary Health Care	\$3,000,000 annually
HRSA, Bureau of Primary Health Care – School Health	\$450,000
HRSA, Health Information Technology Innovations	\$750,000
New York State Area Health Education Center (AHEC)	\$62,113 annually
HRSA HIT Special Congressional Initiative	\$94,352

Signature: \_\_\_\_\_



Date: \_\_\_\_\_

3/18/09

Please attach a copy of this form, along with your curriculum vitae (resume) to your written testimony.

Mr. OBEY. I'm sorry. But thank you.  
And Robert Pestronk.

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WEDNESDAY, MARCH 18, 2009.

**NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH  
OFFICIALS**

**WITNESS**

**ROBERT PESTRONK**

Mr. PESTRONK. Thank you, Mr. Chairman.  
I really have four points to make.

First, that local health departments have a unique and distinctive role and a set of responsibilities in the larger health system and within every community. They are the grassroots entity, source of data for State and Federal departments of health as well.

Second, that local health departments depend upon Federal funding. About 20 percent overall, without Medicare and Medicaid, of the funding for local health departments comes from Federal sources. Yet that funding continues to be inadequate and shrinking, both in real terms and in absolute terms.

Third, that the Nation's recession is further diminishing the capacity of your health departments in three areas: to measure population-wide illness and death, to organize efforts to prevent disease and prolong quality of life and to serve the public through programs in each of your communities. Seven thousand local health department jobs were lost in 2008, and we expect at least that many or more in 2009 to be lost.

Our recommendations are in the written material, and I thank you very much for your time this afternoon.

[The information follows:]



Statement of the

**NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS**  
Washington, DC

Submitted by Robert M. Pestronk, Executive Director  
to the  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives

**FY 2010 Appropriations for Public Health Programs at the Centers for Disease Control  
and Prevention, Health Resources and Services Administration, Office of the Surgeon  
General and Office of the National Coordinator for Health Information Technology**

March 18, 2009, 2 pm

**Summary**

NACCHO recommends essential support for the following programs:

- Preventive Health and Health Services Block Grant
- Healthy Communities
- Racial and Ethnic Approaches to Community Health
- Title V Maternal and Child Health Block Grant
- Public Health Emergency Preparedness Cooperative Agreement
- Advanced Practice Centers
- Medical Reserve Corps
- Public Health Workforce programs
- Health Information Technology programs for public health
- Environmental Public Health Tracking
- Climate Change



The National Association of County and City Health Officials (NACCHO) and the nation's local health departments (LHDs) are grateful to Chairman Obey and the Subcommittee for proposing and supporting prevention and wellness funding through the American Recovery and Reinvestment Act. These funds will help strengthen LHD efforts to reduce infectious disease through immunization and to promote wellness and prevention of chronic disease.

#### **Background**

NACCHO represents the nation's approximately 2,860 local health departments. These governmental agencies work every day in their communities to prevent disease, promote wellness, and protect health. They organize community partnerships and facilitate community conversations to create the conditions in which people can be healthy. The work of local health departments and NACCHO improves economic well-being, educational success, and nation-wide competitiveness community by community.

**LHDs have a unique and distinctive role and set of responsibilities in the larger health system and within every community.** The nation depends upon the capacity of local health departments to play this role well. A LHD is the only local governmental entity that works from a population-wide perspective. LHDs have statutory powers which enable their role and enshrine a duty to serve every person and household in their jurisdiction.

**Funding to local health departments continues to be inadequate** and many people in the United States suffer from conditions whose causes are preventable, whose costs for treatment are unsustainable into the future, and whose treatment is of erratic quality, effectiveness and efficiency. One clear, measured result is that the United States is not the healthiest nation in the world despite higher per capita expenditures than any other nation.

**The nation's current recession further diminishes the ability of local health departments to measure population-wide illness and death, organize efforts to prevent disease and prolong quality of life, and to serve the public through organized programs not offered elsewhere.** Repeated rounds of budget cuts and lay-offs in LHDs continue to erode capacity. Reductions in local and state tax bases further undermine these sources of support. A NACCHO survey found that in 2008, at least 7,000 LHD jobs were lost in 46 states across the country. Far more are expected this year and many LHDs are currently reporting budget cuts in the 20 to 40% range.

Protections people take for granted – from enforcement of rules requiring safe food in restaurants and schools to early identification of disease outbreaks to the expectation that their LHD will examine, discover, and take action – are disappearing. In economic hard times, people are more dependent than ever on their local health departments. Programs offered by LHDs serve as a safety net for people in communities where the numbers of unemployed, uninsured, and under-insured are growing daily, compounding the numbers of formerly working adults who need care.

NACCHO's recommendations focus on the Centers for Disease Control and Prevention (CDC), the Health Services and Resources Administration (HRSA), the Office of the National Coordinator for Health Information Technology (ONC) and the Office of the Surgeon General. Consistent funding with growth over time is needed. NACCHO recommends an overall funding level for CDC of \$8.6 billion not including funding for Vaccines for Children.

***1) Chronic Disease Prevention and Health Promotion*****Preventive Health and Health Services Block Grant: NACCHO recommends: Not less than FY05 funding of \$131 million**

Local public health departments receive approximately 40% of the Preventive Health and Health Services block grant (PHHS) nationally. The proportion received by local health departments varies among states from less than five percent to almost 100 percent. Increasing the availability of flexible funds is particularly important as the gaps in public health protections grow.

PHHS funds enable states to address critical unmet public health needs. Improving chronic disease prevention through screening programs and programs that promote healthy nutrition and physical activity are prime examples of activities to which many jurisdictions devote PHHS funds. Population-based strategies which create the conditions in which people are more likely to be healthy are also supported with these funds. For example, in Brown County, Wisconsin, the local health department implemented science-based policy and environmental changes to improve the health status of the community and supported by PHHS funds. The LHD and the Brown County Walking and Bicycling Advisory Group facilitated the development of a walking and bicycling plan to be used in community design efforts. They have created greater access to walking trails for people with disabilities, and influenced county leaders to take a more balanced approach to transportation.

Flexible PHHS funds allow local priorities and unexpected problems to be addressed. West Nile virus, a fully preventable disease spread to humans by mosquitoes, is one good example. Finally, PHHS funds provide leverage for additional support from non-federal sources. For example, PHHS funds allowed the state of California to establish the Local Public Health and the Built Environment Project, which helps LHDs integrate the principles, findings and science of public health with community design, resulting in communities that are more walkable and conducive to promoting health.

NACCHO also recommends that the Subcommittee include language with the appropriations bill which would require concurrence of LHDs with state public health officials in the uses for and distribution of these funds. Such language has been instrumental in the effective use of preparedness funds, assuring that a reasonable proportion of funds help local communities.

**Healthy Communities: NACCHO recommends: \$75 million**

The Healthy Communities program successfully aligns local stakeholders in communities to address the growing problems of obesity and other chronic diseases. Healthy Communities produces personal, organizational, and governmental policy, systems, and environmental changes that facilitate personal decisions to be more physically active, eat a healthy diet, and refrain from using tobacco. The Healthy Communities program has reached 175 communities since its inception in FY2003 and needs to reach more. With longer time frames intentionally planned at the outset, communities funded by Healthy Communities have demonstrated science-based measurable actions and outcomes that reduce illness and death or the pre-conditions that would otherwise lead to illness and death. Community action has stimulated better personal and professional practice. Communities in this program have shown greater compliance by diabetic patients with routine screenings, a decrease in asthma to rates below the national average, and an increase in those who attempt quitting smoking.

**Racial and Ethnic Approaches to Community Health (REACH): NACCHO recommends: \$60 million**

REACH is an important cornerstone of CDC's efforts to eliminate racial and ethnic health disparities in the United States. By beginning to establish a national infrastructure to promote evidence- and practice-based public health programs, community-based participatory approaches, and the integration of systemic influences, REACH supports and disseminates programmatic activities that are successful in the elimination of racial and ethnic health disparities. REACH is a building block and template for this country's new emphasis on prevention and wellness. Through REACH, LHDs join with other community partners to reduce racial and ethnic health disparities.

**Maternal and Child Health (MCH) Block Grant: NACCHO recommends: \$850 million**

The Maternal and Child Health Block Grant authorized by Title V of the Social Security Act is the only federal program of its kind devoted solely to improving the health of all women and children. With these funds, many LHDs provide maternal and child health services when these funds are allocated to them by states. Unfortunately, these funds have not kept pace with the cost of these services and LHDs are beginning to eliminate or curtail services. Improvements in reducing infant mortality are stalled, low birth weight and preterm births are increasing, and the U.S. ranks 29<sup>th</sup> globally in infant mortality rates. Additionally, racial and ethnic disparities persist across several indicators, with the African-American infant mortality rate double the rate for European-Americans. Increased funding for the MCH Block Grant will help reverse these trends.

**2) Emergency Preparedness**

**Public Health Emergency Preparedness Cooperative Agreement: NACCHO recommends: Not less than FY05 funding of \$919 million**

Federal funding for improving state and local public health emergency preparedness has stalled for the past several years and is substantially down from \$919 million in FY05 to \$746 million in the FY09 omnibus appropriations bill. Last year more than 25% of LHDs reduced their preparedness activities, delayed completion of plans, and/or delayed acquisition of equipment and supplies as a result. Constant readiness for both new and emerging threats requires staff, plans, training and practice, all of which require financial support. The benefits to safety and well-being of local communities are clear when LHDs are prepared and work effectively with their communities to be prepared for all hazards. Reduction in federal financial support has reduced readiness and the capacity to respond to emergencies.

**Advanced Practice Centers: NACCHO recommends: Level funding of \$5.3 million plus inflation adjustment**

The Advanced Practice Center (APC) program funded through CDC provides funds to seven local health departments to develop innovative field-tested tools and models to help other LHDs meet emergency preparedness goals. The APCs are located in Santa Clara County, CA; Cambridge, MA; Montgomery County, MD; Twin Cities Metro, MN; Western New York Public Health Alliance; Tarrant County, TX and Public Health – Seattle and King County, WA. The 70 unique preparedness tools produced to date by the APCs have become essential instruments that LHDs nationwide routinely employ to assess their vulnerability, strengthen their response capacity, and enhance the resilience of their communities and workforce. The APC network

provides a national learning laboratory that creates tools, resources, and technical guidance that can be used for all LHDs and that align with public health preparedness priority areas.

**Medical Reserve Corps: NACCHO recommends: Level funding of \$12.3 million plus inflation adjustment**

The Medical Reserve Corps (MRC) improves the health and safety of communities across the country by organizing public health, medical and other volunteers to serve critical needs. MRC units build response capabilities and enhance capacity to perform daily public health activities in local communities.

For example, MRCs ensure that links with emergency responders are tested and reinforced to assure effectiveness in disasters; immunize vulnerable populations against infectious disease; help run clinics for low income residents, preventing costly and unnecessary hospitalizations; deliver health education to people who are at risk of preventable diseases; and help prepare community organizations, senior centers, schools and healthcare professionals for public health emergencies.

**3) Public Health Workforce**

**Public Health Workforce: NACCHO recommends: \$10 million new funding**

The shortages in the public health workforce have been well-documented, particularly in public health nursing, epidemiology, laboratory science, and environmental health. The nation's wellness depends on a continuing supply of people for this workforce. Additional funding and leadership is required to support a program of training, continuing education, and education for the full range of public health professions and community workers. Section 765 of the Public Health Service Act authorizes grants that would allow state and local health departments to provide training and trainee support. Funds have never been appropriated for this purpose.

**Emergency Preparedness Workforce: NACCHO recommends: \$10 million new funding**

Workforce shortages also exist in the area of public health preparedness. In 2006, the Pandemic and All-Hazards Preparedness Act created two new programs within the National Health Service Corps (NHSC) in the Health Resources and Services Administration (HRSA), yet no funding was appropriated for these programs. Funding would allow expansion of the NHSC on a trial basis to include loan repayment for individuals who complete their service in a state, local, or tribal health department that serves health professional shortage areas or areas at risk of a public health emergency. The second program establishes grants to states to create loan repayment programs. These programs are essential to ensure a workforce trained to carry out specialized tasks in preparedness.

**4) Health Information Technology**

Electronic Medical Records (EMR) and Health Information Exchanges (HIE) and access to health information technology (HIT) can transform public health practice and serve as one supply point for both future information needs and for information of direct value for both clinical and public health practitioners. Unfortunately, at the present time, the major motivation for development of EMR and HIE is often exclusively focused on reducing the cost of health care and improving processes in clinical medicine. Local, state, and federal public health officials rely increasingly on HIT and data systems to assess the health of entire communities

and populations, to provide or recommend focused preventive and treatment services, to evaluate the effectiveness of services and programs, and to identify resources for improving health. Often these needs are neglected.

Through the National Center for Public Health Informatics (NCPHI), CDC provides technical assistance and training to LHDs to strengthen their HIT efforts. Increased funding should be provided to NCPHI for local demonstration sites, which would include LHDs. These sites will demonstrate and assure the value, voice, and involvement of governmental public health officials in the development of HIT that serves multiple purposes and needs. Funding is also needed to increase training and technical assistance for local and state health department informaticians.

NACCHO is grateful that LHDs were included as eligible entities for grants to spur adoption of HIT and strengthen the health information infrastructure in the American Recovery and Reinvestment Act. However, there are many competing priorities for this limited funding. NACCHO recommends that the Subcommittee provide additional direct funding to LHDs through the Office of the National Coordinator for HIT (ONC). As HIT systems are being built, they should be intentionally designed to provide LHDs with the full range of data and reports needed to assess and act on threats to the public's health. ONC should also provide companion grants to LHDs to work directly with health care providers receiving HIT stimulus funding to assure that the software solutions implemented also work with and are connected to the governmental public health infrastructure. Health IT Regional Extension Centers should also receive additional funding with specific funds set aside for public health informatics implementation.

**5) Environmental Health: NACCHO recommends that the** National Center for Environmental Health (NCEH) at CDC receives increased funding to provide direct support and technical assistance to LHDs. Local health departments are involved not only with on-going efforts to assure safe air, safe food, and safe drinking water. LHDs play integral roles in assessment and mitigation of hazardous waste sites. Increased funding would allow NCEH to resume support for community environmental health assessments as well as collaborations between LHDs and local planning departments to improve community design and encourage healthy behaviors.

**Environmental Public Health Tracking: NACCHO recommends: \$50 million**

Enhanced measurement and tracking capabilities are necessary to develop a better understanding of, and track, the connection among the environment in which we live, changes in the environment over time, and human health. Through NCEH, CDC has supported collaboration among state and local partners involved in the Environmental Public Health Tracking Network. Most of the grantees of this program have been states, but local communities provide the data for this network and need increased technical capacity to utilize the Network to determine and, just as important, act on community health priorities.

**Climate Change: NACCHO recommends: \$17.5 million**

In FY09, for the first time, Congress passed a line item appropriation for a Climate Change program at CDC. As more is learned about the effects of climate change on human health, community members will turn to their LHDs for action. Funding to support technical assistance and education will help stimulate action to prevent or mitigate hazards.



## Robert M. Pestronk

As Executive Director for the National Association of County and City Health Officials (NACCHO) in Washington, D.C. since November 2008, Mr. Pestronk represents our nation's local health departments and their staff who protect and promote health, prevent disease, and seek to establish the social foundations for wellness in nearly every community across the United States. Mr. Pestronk received the M.P.H. from the University of Michigan School of Public Health with concentrations in human nutrition and health planning and administration. He received the A.B. in politics from Princeton University.

Prior to his position at NACCHO, he served as Health Officer in Genesee County, Michigan for 22 years where, among other accomplishments, he was recognized for: *establishing* the 26,000 member Genesee Health Plan, some of Michigan's earliest public and work place tobacco control regulations, and Genesee County's Public Health week conference; *introducing* a culture of efficacy, efficiency, accountability and quality improvement within his Department; *reducing* infant mortality rates and the racial disparity among those rates; *increasing* foundation and federal funding for the Department's work; *involving* local residents and his Board in three five-year cycles of successful Departmental strategic planning; and, *creating* productive relationships with university and community-based organizations. His Health Department was fully accredited by the State of Michigan.

He was elected in 2006 to the Board of NARSAD, the Mental Health Research Association. He is a past Board member of the Michigan Health Officers Association (of which he is a past President) and of the Michigan Association for Local Public Health. He is a Primary Care Policy Fellow through the United States Department of Health and Human Services and trained as a Scholar through the Public Health Leadership Institute. He is Past President of the Primary Care Fellowship Society and Past President of the Public Health Leadership Society Council. He was a member of the Institute of Medicine Public Health Roundtable and of the National Advisory Committee for Turning Point: Collaborating for a New Century of Public Health. He was the first President of the Public Health Law Association. He served on the Board of the Greater Flint Health Coalition, the Rotary Club of Flint (Michigan), Priority Children, and Temple Bethel.

Mr. Pestronk received the John H. Romani Outstanding Alumni Award from the University of Michigan School of Public Health Department of Public Health Policy and Administration and was presented the Distinguished Alumnus Award by the University of Michigan School of Public Health. The American Lung Association, Genesee Valley, has honored him as Professional of the Year and subsequently as Health Advocate of the Year.

Bobby's published work includes articles in the Journal of Public Health Management and Practice, the Journal of Law, Medicine & Ethics, the Journal of the American Public Health Association, Health Education and Behavior, Public Health Reports, and the Journal of the American Academy of Nurse Practitioners. Chapters in books include those published by the American Public Health Association and Oxford University Press.

**Subcommittee on Labor, HHS, Education  
and Related Agencies**

**Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

Robert M. Pestronk  
1100 17<sup>th</sup> St. NW 2<sup>nd</sup> Floor  
Washington, DC 20036  
202-783-5550

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.

National Association of County and City Health Officials

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2006?

Yes X      No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

Please see attached.

Signature: \_\_\_



Date: \_3/16/09\_\_\_\_\_

**Attachment A - Witness Disclosure Form  
For: Robert M. Pestronk**

Amount	Source (Agency and Program)	Recipient
\$85,000	DHHS/CDC - Special Report - Lessons Learned and a Compendium of Success Stories - Steps to a Healthier US Program	NACCHO
\$400,000	DHHS/HRSA - Improving Understanding of Maternal and Child Health and Health Care Issues	NACCHO
\$4,845,000	DHHS/CDC - Advanced Practice Centers - Promoting Public Health Preparedness through Local Innovation	NACCHO
\$3,000	DHHS/PSC/SAS/DAM - MRC Region III Conference Planning	NACCHO
\$11,650,000	DHHS/OS - MRC Capacity Development Project	NACCHO
\$20,000	DHHS/CDC - NACCHO Annual 2007 Conference	NACCHO
\$113,302	DHHS/CDC - ASTHO NACCHO 2008 Joint Conference	NACCHO
\$140,000	DHHS/CDC - Injury Prevention and Control Research and State and Community Based Programs	NACCHO
\$198,253	DHHS/CDC - HIV/AIDS Policy Initiative, Building State, County and Local Public Health Infrastructure	NACCHO
\$198,000	DHHS/HRSA - Technical Assistance to Community and Migrant Health Centers and Homeless	NACCHO
\$7,569,934	DHHS/CDC - Building the Nation's Public Health Infrastructure	NACCHO
\$200,000	DHHS/HRSA - Adolescent Health/School-Based Health	NACCHO
\$11,645,393	DHHS/CDC - Building the Nation's Public Health Infrastructure	NACCHO
\$640,000	DHHS/CDC - National Programs to build the Capacity of Societal Institutions That Influence Youth Behavior	NACCHO
\$1,134,131	DHHS/CDC - National Organization for the Dissemination of Effective Strategies for Chronic Disease Prevention and Health Promotion	NACCHO

Mr. OBEY. All right. Thank you, and I apologize again for the screwy schedule we keep around here.  
The Committee is adjourned.

TUESDAY, MAY 12, 2009.

## **MEMBER REQUESTS**

### **WITNESSES**

**HON. SAM FARR, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA**

**HON. MADELEINE BORDALLO, A DELEGATE IN CONGRESS FROM GUAM**

**HON. PETE OLSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS**

**HON. RODNEY ALEXANDER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF LOUISIANA**

Mr. OBEY. This afternoon the subcommittee convenes its Member Day hearing for the fiscal year 2010 budget cycle. I want to welcome Members who will be testifying on behalf of their requests. This hearing is part of the package of additional earmark process reform that I announced earlier this year with Speaker Pelosi that expands on the transparency and accountability measures adopted since January of 2007.

Congressionally-directed funding is part of Congress's power of the purse. At the same time, we have to protect the integrity of the process and ensure the proper use of taxpayers' money. I think that is what this committee has consistently tried to do.

But there is another reason also for this hearing, frankly. I know that some Members have expressed their unhappiness in the past because we have not been able to fund some of their significant priorities. Because of that, and because we have got a finite amount of resources that can be devoted to these projects, I wanted to give any Member who had a special interest in the projects that they are promoting. I wanted to give them an opportunity to appear before the committee to make their case, and I appreciate the fact that you have come here today.

So why don't we simply start with Mr. Farr? Why don't you give us whatever information you care to impart on your project?

Mr. FARR. Thank you very much, Mr. Chairman. This is the first time I have appeared on behalf of one of my asks, and I appreciate you giving me this opportunity.

This one is really very, very important. It is a million and a half dollars for a program called the Silver Star Program. It is in Monterey County. And just to put you in perspective, Monterey County is in the central part of California. It is the Salinas Valley, which is a good chance that the food you eat for lunch and dinner tonight will come from the Salinas Valley. It is the biggest agricultural area in the United States. It is row crops, and all of those crops have to be taken out by trucks. So you have about 5,000 trucks coming in and out of Salinas every single day.

It is also the home, Monterey County, of the largest State prison in California.

And what has happened over the years, because of this, low-income ag workers, culture of poverty, it has really become a center of the State for a huge international gang war that is being fed by the cartels between the Nortenos from the north and the Surtenos from the south. And we are just geographically located right in that midspot.

And what has happened is the small town, the City of Salinas, about 150,000, largest town in my district, but certainly small in the big perspective, is having the responsibility of breaking the back of international cartels with just local law enforcement resources. And they can't do it alone. So I have gotten very involved in this because I used to serve in local government. The fact is, if you want to stop this, and I was looking at Dwight D. Eisenhower's quote right here, there should be an unremitting effort to improve those health, education and social security programs which have proven their value; to bring all of those assets, that are at, some at the county level, some at the city level, some at the State level and some at the national level, to try to develop a really comprehensive package to try to stop organized crime.

And how are we doing that? We are taking kids out of the breeding grounds for these gangs, which are their neighborhoods, early in the morning and taking them to this Silver Star Program, which deals with education; truancy abatement; health care and addiction services; family counseling; career counseling; job training; psychiatric care; mental health and related care. It is a one-stop program that is really successful.

And what we are trying to do is, there is a surge going on because we are finding now second- and all third-generation; imagine in your district if you had had a killing a week in a small town. That is what has happened. We have had 15 killings this year. It is shocking the community. It is hurting the economic development of the community, on top of what is, this is the city that ranked 12th in the Nation in drop of home prices, and one of the top cities in foreclosures. We are designated as one of the High Intensity Gang Area, the HIGA jurisdiction. There were 77 robberies in Salinas; 40 of them committed by firearms.

So we think we have got some ability to really tackle this thing in a comprehensive way. And that is why I am putting all my effort into this earmark, to try to make sure that we can pull together all the resources, and particularly those of the Federal Government.

I might just conclude by telling you that I have done one thing that I think is going to be really effective. We have the Naval Postgraduate School in Monterey County; it is in Monterey, not in Salinas. That school has, inside the school, a center for Homeland Security, where you have both the military folks and the civilian folks looking at, what are the root causes of violence around the world? They are the ones that are coming up with plans of, how do we bring peace to Afghanistan and Iraq through a combination of military and civilian activities?

I have sort of said to the school, if you are so smart, why don't you go over and look at a town in there and look at the assets of

what this is. This is like a town in a foreign country with probably more assets than most foreign countries. But if you can figure out how we can curtail the root causes of violence that are culturally driven and poverty driven and so on, and deal with the issues that people deal with, illegal guns, drugs and so on, maybe we can, if we can be effective in our own hometown, maybe we can be more effective overseas, particularly in Afghanistan.

So hopefully this is going to be the year where we bring all of that together, where the leather meets the road. And I would appreciate your consideration of this earmark.

[The information follows:]

**SAM FARR**  
17TH DISTRICT, CALIFORNIA

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEES:

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FOOD ADMINISTRATION, AND RELATED AGENCIES

HOMELAND SECURITY

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REP. SAM FARR

Testimony before the Appropriations Subcommittee on  
Labor, HHS, Education and Related Agencies

May 12, 2009

Thank you, Chairman Obey, for this opportunity to testify before you today about  
a specific appropriations request I have submitted to the subcommittee.

That request is for \$1.5 million in FY 2010 to underwrite the Silver Star Gang  
Prevention and Intervention Program.

As you are aware, this subcommittee has been very generous to the Silver Star  
program in the past. I am grateful to you for that, as is my community of Monterey  
County.

But even though the subcommittee has been responsive to my requests for help  
with Silver Star, the need remains and I am here today to implore you to continue funding  
for the program.

The Silver Star program is a county-run anti-gang program and is a unique  
comprehensive approach to beating back gang activities in impacted communities. It is a  
holistic program in which familial, educational, medical and social services are provided  
on an individualized basis to gang members. It has an incredibly high success rate but  
the number of youth who could use its help far outnumbers the ability of the program to  
accommodate.

In Monterey County which I represent the gang problem is not unique in its  
manifestation, but it is unique in its origins.

That is because the city of Salinas is the battleground where gang violence is  
driven by a struggle between gangs whose influence and activities cross not just local but  
*international* boundaries (the Norteños and the Sureños).

Specifically, Monterey County has been designated as one of the "High Intensity  
Gang Areas" (HIGA) jurisdictions, based on the high number of gang-related homicides  
per resident. The influence of gangs on local at-risk youth is strong, and there are starting  
to appear second and third generation gang members. In this primarily Hispanic region,  
the two major rival gangs are Hispanic gangs, the Norteños and the Sureños, both with  
strong ties to the two state prisons - Salinas Valley State Prison (SVSP) and the



California Training Facility (CTF) – both of which are located in Monterey County. Increased violence on the streets is mostly determined by the regional power struggle between the two gangs and the Norteños' fight for local control. The gangs' span of activity and influence crosses over county boundaries and stretches north and south of the area. Accordingly, Silver Star's efforts to reduce gang involvement provide benefits that go beyond the County's borders and support regional and statewide anti-gang efforts.

Lest you think the money the subcommittee has provided in the past has had no impact, let me assure you – it has been very, very effective. But because of the nexus of these gangs in the area Silver Star has been overwhelmed. Consequently, my request is a lot like a "surge" request. Silver Star needs extra resources to break the back of this increased gang presence. If Silver Star can successfully interrupt the influence of these gangs and disrupt their street activities we will hit that critical "tipping point" to freeing the community of this gang scourge.

In addition, just so you know, my request to your subcommittee does not stand alone. I am working with the CJS Subcommittee for similar funding to combat gang activity from the law enforcement side of the equation.

The Silver Star request to your subcommittee is very important to me and is my number one priority. I hope you will give this project your approval and give Monterey County and the city of Salinas the tools they need to stop children and youth from succumbing to the siren song of gangs.

Thank you.

Mr. OBEY. I appreciate that.

Any comments?

Mr. TIAHRT. I think that this is, human nature is human nature. I think you made a good point about if we are successful in our own communities, we can transfer this to elsewhere.

One of the things that we have noticed in Wichita, and it probably is true with human nature, is that many gangs have a strong personality that stirs everybody up. And when they take that strong personality out of that setting, many of the kids just go back to their regular lives, and they quit stealing. They are not as involved in drugs. It is sort of what gives them an opportunity to get away from that strong personality. And it would be nice if your research would confirm that that is an effective way of dealing with gangs.

Mr. FARR. We have already done that, and I would be glad to share that with you. One of the difficulties you have is, because there is so much peer pressure on gangs, I mean, I am told that there is about 100 different social gangs, little kids. These houses are so crowded, kids play in the street. They are starting at young ages. You get this buddy on the street, a little bit older kid, who becomes your protector for that little block. And that is sort of the social gangs that you belong to. And then, maybe, as you get older and into your teenage years, and the problem with the Nortenos and Surtenos is one of your sort of life passages is you have got to kill somebody.

And what you find, the kids who are taken out are saying, we don't want to go back in. We love this program. We love the diversion. We love being on probation. Don't put us back in the high school.

So we are going to have to figure out ways to continue that alternative success rather than, you know, just take them out and throw them back in. Then you are going to get recidivism. Thank you.

Mr. OBEY. Thanks for your time, Sam.

Next, our colleague, Madeleine Bordallo.

How is Guam doing these days?

Ms. BORDALLO. It is doing very well, and it still afloat, in spite of the large build-up that we expect.

Good afternoon, Chairman Obey and Ranking Member Tiahrt. My testimony today emphasizes four of the priority projects that I have requested and also includes a request for legislative language. These were outlined in my letter to the subcommittee submitted last month, but given the time constraints, my testimony today will focus on the priorities most in need of Congressionally-directed funding.

The first priority, Mr. Chairman and Ranking Member, is a project that I request for an appropriation of \$725,000 to renovate and expand a nursing education and training laboratory at the University of Guam. The University of Guam provides the only nursing education program on the island and in the region, and there is no shortage of interest in the nursing program. But due to the overwhelming number of applicants this past academic year, the nursing program had to turn away individuals who were interested in pursuing a degree in nursing.

By renovating the laboratory, the university expects to expand the number of graduates and also provide them with an environment that will help them to continue developing their skills. Skill enhancement, in turn, enables its nursing graduates to provide a more current and more sophisticated level of the care for the people of Guam. And this was a request from a former Member of Congress who is now the president of the University, the Honorable Robert Underwood, who I am sure you know, Mr. Obey.

The second priority project that I request is for \$300,000 for a collaborative project entitled the Guam Seamless Education Path Program, between the public school system of Guam, the Guam Community College and the University of Guam. This important pilot program, if funded, will assist students enrolled in Guam's public elementary and secondary schools in identifying and pursuing a college or professional trade education.

This project is timely, given the current statistics presented by the superintendent of the public schools, which indicate that only 65 percent of public school students completed high school last year, and only a third of these students are expected to pursue higher education.

Overall, only one in five Guam public high school freshmen enrolled in a college or university. So as a collaborative program between the three main educational institutions on Guam, the Guam Seamless Education Path Program is essential to enhancing the overall educational outcomes for all the students on Guam.

Now, the third priority project that I request for, Mr. Chairman and Mr. Ranking member, is for \$300,000 to support training programs in the construction and the electrical trades at the Guam Community College. This funding would be used to expand the current program through recruitment of students and the purchasing of educational materials. There is a great need for the Guam Community College to expand its existing programs because of the demand for workers with these specific skill sets on Guam.

Guam is increasingly significant as a result of the greater Federal investment in construction programs on Guam. Based on current measures, there is a shortage of trained workers to build the facilities as a result of the oncoming military buildup. With the booming construction activity, including the execution of \$747 million in military construction projects on Guam that is included in the President's budget request for Fiscal Year 2010, the funding I am requesting would expand existing job training programs offered in the construction and electrical fields in order for residents of Guam to be trained for and to compete for these jobs.

And my fourth priority project is for \$200,000 to the Chamorro Studies and Special Projects Division of the Guam public school system to implement innovative language instructional programs promoting and preserving our Chamorro language and our culture. This would be the second phase of the project, as this has been congressionally funded in the past, in 2007. Chamorro, our language, is traditionally an oral language, and there is a lack of books, magazines, audio-visual and other media resources in Guam's indigenous language, causing a decline in Chamorro fluency and literacy among younger generations. So funding will help continue the efforts to revive and maintain the indigenous language and the cul-

ture of Guam by providing additional resources to develop and implement innovative curriculum and unit lessons for Chamorro language instruction. Such curriculum may involve the production of Chamorro language audio and video programs and the development of new Chamorro language and grammar books and activities.

And finally, a language request. I respectfully request that the bill include a section with language authorizing the outlying areas to consolidate funds received as a result of its enactment, as well as any remaining funds received under prior year appropriation acts for the Department of Education pursuant to Title V of the Elementary and Secondary Education Act. Now, similar bill language was enacted into law as Section 306 of the Department of Education Appropriations Act of 2009.

The loss of consolidation authority under Title V resulted two budget cycles ago from a realignment of national budget priorities under the budget submitted to Congress by the President. So the Department of Education continues to work with the local educational agencies in the outlying areas to determine the best means for consolidation, flexibility of Federal funds received under the Elementary and Secondary Education Act.

Until such time as an alternative solution is identified and agreed to, it is important that the outlying areas and the Department of Education be granted the legal authority to an option of consolidating grants in a manner similar to past practices.

So I want to thank you, Mr. Chairman and Members, for your consideration of all the requests I have submitted to the committee, and for your attention to the health, educational and work force needs of Guam. And I appreciate the assistance that the subcommittee has provided in the past, and hope that you will include Congressionally-directed funding for the projects I have outlined today.

[The information follows:]

**STATEMENT OF HON. MADELEINE Z. BORDALLO  
MEMBER REQUESTS HEARING  
TESTIMONY BEFORE THE  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES  
COMMITTEE ON APPROPRIATIONS  
May 12, 2009**

Good morning Chairman Obey and Ranking Member Tiahrt. I welcome the opportunity to appear before you today to underscore the importance of this Subcommittee in providing funding in fiscal year 2010 for the important education, healthcare and workforce training projects that I have requested for Guam. Given its territorial status, Guam is at an inherent disadvantage under program formulas in receiving federal assistance to address pressing public health, education and employment needs. My testimony today emphasizes four of the priority projects I have requested and also a request for legislative language that was included in my letter submitted to the Subcommittee last month. Given the time constraints, I cannot go into detail about all my project requests, therefore my testimony focuses on the priorities most in need of Congressionally-directed funding.

At the start, let me state that Guam is in the midst of an unprecedented military build-up and is preparing to host elements of the III Marine Expeditionary Force which will be relocated from Okinawa, Japan. My project requests, if funded, would be important federal investments in healthcare, education and labor for the community on Guam to keep pace with a growing population and the demands associated with the military build-up.

The first priority project that I request is for an appropriation of \$725,000 to renovate and expand a nursing education and training laboratory at the University of Guam. Like many parts of the country, Guam is currently facing a nursing shortage which will continue to rise with the military build-up. The University of Guam provides the only nursing education program on the island and in the region. Modernizing this education and training laboratory will allow current and future students the opportunity to

enhance their studies through state of the art technology. If funded, the University of Guam will be able to better develop a more highly trained nursing workforce and provide new opportunities for the residents of Guam to prepare for professional health careers. There is no shortage of interest in the nursing program. Due to the overwhelming number of applicants this past academic year the nursing program had to turn away individuals who were interested in pursuing a degree in nursing. By renovating the laboratory, the University expects to expand the number of graduates and also provide them with an environment that will help them to continue developing their skills. Skill enhancement, in turn, enables its nursing graduates to provide a more current and more sophisticated level of care for the people of Guam.

The second priority project that I request is for \$300,000 for a collaborative project entitled the "Guam Seamless Education Path Program" between the Guam Public School System, the Guam Community College and the University of Guam. This important pilot program if funded will assist students enrolled in Guam's public elementary and secondary schools in identifying and pursuing a college or professional trade education. This project is timely, given the current statistics presented by the Superintendent of the Guam Public School System, which indicate that only 65 percent of public school students completed high school last year and only a third of these students are expected to pursue higher education. Overall, only one in five Guam Public High School freshmen go onto enroll in a college or university. As a collaborative program between the three main educational institutions on island, the Guam Seamless Education Path Program is essential to enhancing the overall educational outcomes for all students on Guam.

The third priority project that I request is for \$300,000 to support training programs in the construction and electrical trades at the Guam Community College. This funding would be used to expand the current program through recruitment of students and the purchasing of educational materials. There is a great need for the Guam Community College to expand its existing programs because the demand for workers with these specific skill sets on Guam is increasing significantly as a result of greater

federal investment in construction projects on Guam. Based on current measures, there is a shortage of trained workers to build the facilities as a result of the military buildup. With a boom in construction activity – including the execution of \$747 million in military construction projects on Guam that is including in the President’s budget request for fiscal year 2010 – the funding I am requesting would expand existing job training programs offered in the construction and electrical fields in order for residents of Guam to be trained for and to compete for these jobs.

My fourth priority project is for \$200,000 to the Chamorro Studies and Special Projects Division of the Guam Public School System to implement innovative language instructional programs promoting and preserving the Chamorro language and culture. The Chamorro language is the indigenous language of Guam. As Chamorro is traditionally an oral language, there is a lack of books, magazines, audio, visual and other media resources in Guam’s indigenous language causing a decline in Chamorro fluency and literacy among younger generations. Funding will help revive and maintain the indigenous language and culture of Guam by providing additional resources to develop and implement innovative curriculum, syllabi, and unit lessons for Chamorro language instruction. Such curriculum may involve the production of Chamorro language audio and video programs and the development of new Chamorro language and grammar books and activities.

Finally I respectfully request that the bill include a section with language authorizing the Outlying Areas (American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the Virgin Islands) to consolidate funds received as a result of its enactment as well as any remaining funds received under prior year appropriations acts for the Department of Education, pursuant to 48 U.S.C. 1469a, under Part A of Title V of the Elementary and Secondary Education Act (ESEA). Similar bill language was enacted into law as Section 306 of the Department of Education Appropriations Act, 2009 (Public Law 111-8). The loss of consolidation authority under Title V of the ESEA resulted two budget cycles ago from a realignment of national budget priorities under the budget submitted to Congress by the President. The

Department of Education continues to work with the local educational agencies in the outlying areas to determine the best means for consolidation flexibility of federal funds received under the ESEA. Until such time as an alternative solution is identified and agreed to, it is important that the outlying areas and the Department of Education be granted the legal authority to and option of consolidating grants in a manner similar to past practice.

Thank you for your consideration of all of the requests I have submitted to the Committee and for your attention to the health, educational and workforce needs of Guam. I appreciate the assistance that the Subcommittee has provided in the past and hope that you will include Congressionally-directed funding for the projects I have outlined today in the bill will soon markup.



Mr. OBEY. Thank you.

Let me simply say with respect to your point on nursing, the Department of Labor statistics show that even though we have a huge wave of unemployment in this country, one of the few areas of job growth in the economy is in the area of health care professions, especially nursing.

Ms. BORDALLO. And social workers.

Mr. OBEY. Well, I have to be for social workers because my wife is a social worker.

But with respect to nursing, if we are serious about health care reform, we are going to have to expand the capacity of the health care system through developing a lot more primary care physicians and other health professions, including nursing. So I appreciate your being here today.

Any other comments?

Okay. Next, Congressman Olson.

Mr. OLSON. Chairman Obey, Ranking Member Tiahrt, Congressman Rehberg, thank you for the opportunity to speak with you today in support of a very worthwhile project that needs funding in the Fiscal Year 2010 Labor/HHS Appropriations bill.

And this is the only request I have before the committee and humbly feel that the benefits of this program justify the use of Federal taxpayer dollars. Within the Department of Labor, Employment and Training Administration, Training and Employment Services Account, I am requesting \$350,000 for San Jacinto College for a project designed to help displaced workers in the Houston area obtain training to re-enter the work force in high-demand positions. The college is going to match this level of funding with \$350,000 of their own.

This project would train new workers and retrain and upscale existing workers to become welders, pipe fitters and nondestructive testing personnel for the U.S. petrochemical industry. This initiative is not important only to the economy of the 22nd District of Texas but to our Nation as well.

The mission of San Jacinto College is to deliver accessible, affordable high-quality secondary education programs designed to meet the needs of the citizens of southeast Texas and America. The college's primary focus is helping students achieve their personal and professional goals, create seamless transitions among educational levels, and to prepare students to enter the job market or transfer to 4-year institutions. Through its programs and services and partnerships with industry, the college supports the economic growth of the community, the region and the Nation as well.

Current labor and skills shortages in key occupational clusters are inhibiting economic development. The Houston metropolitan area is fortunate in that workers can be trained in cross-cluster skills in order to be employed in either the aerospace or petrochemical industries. By combining training and education with specific career pathways that lead to advanced skills, entry-level workers can then move through a predetermined pipeline to higher-skilled and higher-paying jobs.

Among the industry employment positions to be advanced by the Workforce Development Training Project are nondestructive testing technicians, pipe fitter's helper, welder's helper, combination weld-

er, stick pipe welder and structural welder. That is all I know about welding.

As workers are trained for new jobs, their existing positions become available, opening up vertical movement and higher wages for others.

The project will also enable the college instructors to move from a board-drafting lab to a computer-aided drafting lab and will involve training in basic math skills. Many displaced workers need only basic math skills to qualify for workforce training programs so they may re-enter the work force with more marketable skills.

The Workforce Development Training Program enjoys the support and involvement of San Jacinto College's public and private-sector partners, a list of whom I would like to include for the record.

This is the proverbial win-win situation in my mind. It helps provide jobs to those who need them, while supplying a skilled work force to an industry that is short of workers and can help fuel our Nation's economic recovery. The program is slated to help 600 students upon its creation to start filling the thousands of available positions in the region.

I come before this committee humbly and with the utmost respect for the allocation of taxpayer funds, and firmly believe that this project is a wise investment for our Nation to further educate a needed work force and to help strengthen our national economy.

And thank you for the opportunity to testify before you today. I am happy to answer any questions.

[The information follows:]

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 SUBCOMMITTEE ON SPACE AND AERONAUTICS  
 Room 14-1020  
 COMMITTEE ON HOMELAND SECURITY  
 COMMITTEE ON TRANSPORTATION  
 AND INFRASTRUCTURE

Testimony Before Appropriations Committee, Subcommittee on Labor, Health and Human  
 Services, Education and Related Agencies  
 Member Hearing  
 Tuesday, May 12, 2:00 pm

Chairman Obey, Ranking Member Tiahrt, members of the subcommittee, thank you for the  
 opportunity to speak with you all today in support of a very worthwhile project that is seeking  
 funding in the FY10 Labor/HHS Appropriations Bill.

I only have one request of this subcommittee, and humbly feel that the benefits of this program  
 justify the use of federal funds. Within the Department of Labor, Employment and Training  
 Administration-Training and Employment Services account, I am requesting \$350,000 for San  
 Jacinto College for a project to help displaced workers in the Houston area obtain training to  
 reenter the workforce in high-demand positions. This project would train new workers and  
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The mission of San Jacinto College is to deliver accessible, affordable, high-quality post-  
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Current labor and skill shortages in key occupational clusters inhibit economic redevelopment.  
 The Houston metropolitan area is fortunate in that workers can be trained in cross cluster skills in  
 order to be employed in the aerospace or petrochemical industries. By combining training and  
 education with specific career pathways that lead to advanced skills, entry level workers can then  
 move through a pre-determined "pipeline" to higher skilled and higher paid jobs.

Among the industry employment positions to be advanced by the Workforce Development Training Project are Non-Destructive Testing Technician, Pipe-Fitter's Helper, Welder's Helper, Combination Welder, Stick Pipe Welder, and Structural Welder. As workers are trained for new jobs their existing positions become available, opening up vertical movement and higher wages for other workers.

The project will also enable the College's instructors to move from a board-drafting lab to a computer-aided drafting lab, and will involve training in basic math skills. Many displaced workers need only basic mathematics skills to join workforce training programs so that they may enter the workforce with marketable skills.

The Workforce Development Training Project enjoys the support and involvement of San Jacinto College's public and private sector partners in the Houston metropolitan area, a list of whom I would like to include for the record.

This is a proverbial win-win situation. It helps provide jobs to those who need them while supplying a skilled workforce to an industry that is short of workers and can help to fuel our economic expansion. The program is slated to help 600 students upon its creation to help fill thousands of positions in Harris County.

I come before this committee humbly and with the utmost respect for the allocation of taxpayer funds, however I firmly believe this project is a wise investment to further educate a needed workforce to help strengthen our local and national economy.

Thank you for the opportunity to testify before you today.

Private Sector Partners for the Workforce Development Training Project at San Jacinto College:

Shell Oil Company, Odfjell Terminals, Chevron Phillips, Dow Chemical Company, Bayer, DuPont, Rohm and Haas, Waste Management, Dixie Chemical Company, the Lubrizol Company, Texas PetroChemical, Valero , Reliant, the WorkSource Gulf Coast Workforce Board, Lee College, North Harris Montgomery Community College District, Kaneka Texas Corporation, the East Harris County Manufacturers Association, the Houston A+ Challenge, Southwest Shipyard, the Economic Alliance Houston Port Region, Air Products, Albemarle, CenterPoint Energy, Invista, and NRG Texas.

Mr. OBEY. Thank you.

I would simply observe, given your comments on welding, I have never seen a community college in my district that feels that it is producing enough welders. There is a constant demand for them.

Mr. OLSON. Yes, sir. Certainly with our petrochemical industry there in the greater Houston area, they need more than they can get. The pipeline can't get full enough. Thank you.

Mr. OBEY. Okay. Thank you very much. Appreciate your time.

Our colleague, Mr. Alexander.

Mr. ALEXANDER. Thank you, Mr. Chairman and Mr. Tiahrt and the Ranking Member on the Louisiana Purchase Delegation.

I am here today, my number one programmatic request was for Even Start. And the President has zeroed that out, perhaps because it looked like a duplicate program.

But Congress must continue to support family literacy programs as an important delivery model in the provision of adult education and early childhood services.

There is a direct correlation with the education of the parent, the poverty status of the home, and the likelihood of the child's success in school. We must focus on the interconnectedness of the program, which will lead us to real long-lasting solutions, educating the entire family.

Adult education does just what it emphasizes. It educates the adult, and early childhood likewise educates the young child. But to make a difference, we must educate the family. By addressing the needs of parents and children simultaneously, we are outperforming stand-alone programs.

Even Start participants are 13 percent poorer than Head Start families, and over 75 percent of our participants have not gone beyond the 9th grade. Despite these obstacles, families exceed state benchmarks in adult education proficiency, preschool vocabulary, and preschool alphabet knowledge. As a result, more adults are obtaining their GEDS and vocational credits, making them more employable. And our children are entering school ready to learn and equal to their peers of higher socioeconomic background.

No other program is evaluated as deeply as family literacy as to the impacts of the family, because no other program does what is being done, delivering services from birth to through adulthood. Losing Even Start will impact services to families that I have described.

Thank you, Mr. Chairman.

[The information follows:]

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 SUBCOMMITTEE ON SPACE AND AERONAUTICS  
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 AND INFRASTRUCTURE

Testimony Before Appropriations Committee, Subcommittee on Labor, Health and Human  
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 Member Hearing  
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 District of Texas.

The mission of San Jacinto College is to deliver accessible, affordable, high-quality post-  
 secondary education programs designed to meet the needs of the citizens of Southeast Harris  
 County. The College's primary focus is helping students achieve their personal and professional  
 goals, create seamless transitions among educational levels, and to prepare students to enter the  
 job market or transfer to four-year institutions. Through its programs and services, and  
 partnerships with industry, the College supports the economic growth of the community and the  
 region.

Current labor and skill shortages in key occupational clusters inhibit economic redevelopment.  
 The Houston metropolitan area is fortunate in that workers can be trained in cross cluster skills in  
 order to be employed in the aerospace or petrochemical industries. By combining training and  
 education with specific career pathways that lead to advanced skills, entry level workers can then  
 move through a pre-determined "pipeline" to higher skilled and higher paid jobs.

Mr. OBEY. Thank you.

As you know, our old colleague, Bill Goodling, cared strongly about Even Start. He worked for it when he was ranking member and chairman of the Educational Labor Committee in the House, and he is still putting in a pitch for it whenever he can. I am sure he would be happy with your testimony today.

Any others?

Well, that represents all of the witnesses we have before us today. I thank you for showing up, and we will see you on the floor Thursday.

Congressman Steve Cohen  
9<sup>th</sup> District, Tennessee  
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Mr. Chairman, I want to thank you for the opportunity to express my support for the projects that I have submitted on behalf of my constituents of Tennessee's 9<sup>th</sup> Congressional District.

The projects I have submitted will address a myriad of issues facing my constituency. The educational programs for which I have requested funding are the Memphis Career Connection program, the Expansion of the Building Dreams Program, and the National Civil Rights Museum Education and Special Projects Program. Funding for the Memphis Career Connection Program will enable the Memphis City Schools system to operate an afterschool initiative that will allow students to connect with the business and higher education communities, strengthening the students' drive to attend college and pursue their chosen careers; students will be encouraged to develop first-hand knowledge of various careers through mentoring, work projects, and internships. The Expansion of the Building Dreams Program will expand existing program services for people with developmental disabilities. Finally, the funding appropriated for the National Civil Rights Museum Education and Special Projects Program will allow this internationally recognized landmark and museum to continue to provide top-notch programs related to our country's history of civil rights.

I have also requested funding for many healthcare initiatives in my district. Two of these address infant mortality in Memphis; the Infant Mortality Initiative at the Centering Pregnancy Program in Shelby County and the LeMoyne-Owen College Health Disparities/Wellness Community Participatory Project. Memphis has the highest infant mortality rate of any city in the United States and I fully support the funding of these projects to help address the devastating trend that affects so many of my constituents. Another healthcare initiative for which I have requested funding is the Pediatric Echocardiogram Replacement at LeBonheur Children's Hospital. LeBonheur requires this funding to provide the best care for its young patients.

Additionally, I have requested construction funding for the Community Health Building at the University of Memphis, the Emergency Room Expansion Project at the Regional Medical Center, the Southwest Tennessee Community College of Nursing and Biotechnology Program Expansion Extension, the InMotion Sustainability Campaign, and the University of Tennessee-Baptist Memorial Hospital Research Park. Funding of these important projects will improve many educational and healthcare facilities in my district that will benefit my constituents for years to come.

All of these programs are worthy of receiving the funding necessary to sustain them and I do not hesitate to lend my support. I thank you for your consideration of my requests and I look forward to the Subcommittee's favorable funding authorization for the 9<sup>th</sup> District of Tennessee and my constituents.



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**Congress of the United States**  
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HIGHWAYS AND TRANSIT

RAILROADS, PIPELINES  
AND HAZARDOUS MATERIALS

Chairman Obey, Ranking Member Tiahrt and Members of the Subcommittee: **COMMITTEE ON STANDARDS  
OF OFFICIAL CONDUCT**

I am pleased to provide my testimony in support of the Education for Democracy Act (ESEA II, Part C-3) in the FY2010 appropriations cycle. As a longstanding supporter of Education for Democracy programs like We the People: The Citizen and the Constitution, Project Citizen and the School Violence Prevention Demonstration Program, I have seen the benefits paid to teachers and students in the Fifteenth District of Pennsylvania participating in these initiatives.

The Education for Democracy Act employs programs proven to increase students' fundamental understanding of democracy, improve the school environment and increase academic achievement in all content areas, including reading and writing. The principal goals of these worthy programs are to help students develop:

- An amplified understanding of the institutions of constitutional democracy and the fundamental principles and values upon which they are founded;
- The enthusiasm to use democratic procedures for making decisions and managing conflict; and
- The skills necessary to participate as effective and responsible citizens.

The Allentown School District (ASD) in the City of Allentown, Pennsylvania has instituted the Education for Democracy School Violence Prevention Demonstration Program (SVPDP) across grade levels. ASD is the fourth largest school district in the Commonwealth, serving over 18,000 students with forty-one countries represented throughout the student population. Despite the natural challenges accompanying the district's varied demographics, SVPDP is developing and nurturing positive behavior in the classrooms.

SVPDP provides in-depth training for the ASD teachers participating in the program, emphasizing critical thinking, cooperative learning, group problem solving and performance based assessment. Program research demonstrates positive developments in students' civic knowledge and attitudes as they relate to tolerance for new ideas, civic responsibility, authority and the law, as well as social and political institutions. Last year, over 9,000 students across the district participated in culminating SVPDP events at the conclusion of the school year, showcasing their civic knowledge in mock trials and hearings. On June 3, 2009, the Allentown School District will celebrate Civic Education Day to recognize the efforts of students and staff for their work in Civic Education throughout 2008/2009 academic year.

Additionally, Allentown School District has been publicly recognized for their efforts in civic education. In October 2008, the school district accepted the Compass Award for effectively promoted civic engagement in its community, serving as civic leader, and role model. The District has promoted a lifelong love of learning, enabling our City's children to become competent adult citizens living and working in a global society and has done so while working hard to provide a safe, supportive environment for learning. This recognition is indicative of the students' commitment in applying the concepts taught in their classrooms to their time spent in extracurricular and community activities. I would be remiss if I didn't express my appreciation for the teachers, faculty and administrators' dedication to equipping their students with an appreciation and understanding for civic education during such an impressionable time during their academic careers.

I ask that Members of the Subcommittee consider the positive and lasting effects of the initiatives, like SVPDP, within Education for Democracy Act on the generation of students moving through our elementary and secondary schools when considering the FY2010 funding level for this program. Thank you for taking the time to consider my experience and testimony regarding civics education and impact it is having on a community in my district.

Charles W. Dent (PA-15)

**Testimony of Congressman Paul E. Kanjorski****Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies****May 12, 2009**

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As the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies considers Members' fiscal year 2010 Appropriations requests, I would like to take this opportunity to highlight three vitally important projects in my Congressional District. I appreciate the opportunity to submit testimony to the Subcommittee and I thank each Member for their previous support of projects in my District. While I am only providing additional information on three projects, all of the requests that I have submitted have considerable merit and I urge you to give them full and fair consideration.

The first project I am requesting funding for is the former Hazleton Area High School Auditorium now the Elementary/Middle School Auditorium. In 1926, the Hazleton Area School District built the Hazleton Area High School. This high school building was exceptionally unique because of its collegiate gothic style architecture and became known as the "Castle on the Hill." Having toured the facility several times myself, I can attest to its exceptional structural design. For the past 80 years, this building has been a landmark in the City of Hazleton, which is one of the most populous cities in my Congressional District.

Unfortunately, over the years, the historic school building was poorly maintained due to a weak local economy and increased cost of repairs. The Castle doors were shut in the early 1990s because it could not provide students with an acceptable learning environment. As the building laid dormant and decaying, several area residents voluntarily cared for the building in the hopes of it being restored in the future. A grassroots movement led by a local historical society, concerned citizens, and former graduates urged the school district to restore the Castle and use it to accommodate the recent population increase in the City of Hazleton. Rarely in my term of office have I seen such overwhelming community support as I have seen for this project.

The activist group was able to convince the school district to restore the Castle, and the school district ultimately spent over \$35 million for a complete overhaul of the building. In 2007, the school district completed the majority of the renovations and the former high school building has become the newest Elementary/Middle School in the Hazleton Area School District. Approximately, 1,000 students, grades 3 through 8 attend school at the Castle.

In recognition of the Hazleton Area School District's restoration work on the Castle, it was awarded the 2007 Pennsylvania Historic Preservation Award. In addition, the Pennsylvania Department of Education is using the Hazleton Area School District's restoration plan as an example for other school districts in the Commonwealth of Pennsylvania.

One portion of the building that is still undergoing construction, however, is the auditorium. It is my understanding that the physical renovation of the auditorium will be completed in the next several months. The school district has informed me that it plans to expand its theater, dance and arts education programs for students when the auditorium renovations are complete.

As a result, for fiscal year 2010, I am respectfully requesting \$700,000 for the Hazleton Area School District to purchase equipment to begin implementation of its theater, dance and arts education programs that will expand learning opportunities and allow students to put on stage dramatic performances.

The second project I would like to bring your attention to is the Northampton Community College Monroe County Campus. Monroe County is one of the fastest growing counties in the Commonwealth of Pennsylvania and is in need of additional secondary education services to keep pace with the population growth. The funding I am requesting will be used by Northampton Community College to purchase new classroom equipment that will be used at its existing campus and transferred to the new Monroe County campus when construction is completed.

For more than 40 years, Northampton Community College (NCC) has been serving the educational workforce needs of Northeastern Pennsylvania. NCC strives to serve all segments of the community by providing educational services where needs are greatest. The original NCC campus is located just outside Monroe County, which is part of my Congressional District.

In 1988, Northampton Community College began providing the residents of Monroe County with access to higher education by opening a satellite campus in Tannersville, PA. Five years later, the Monroe Campus reached full branch status. Since that time, NCC has experienced a steady increase of students from school districts across Monroe County. Enrollment of the Monroe Campus grew from 92 students in 1998 to 2,045 today. If enrollment continues to increase at this rate, it could push the Monroe Campus enrollment to over 5,000 by 2012. Monroe County residents now account for 25 percent of NCC's overall enrollment, while 19 percent of all Monroe county graduates attend NCC.

With the need to expand educational services in Monroe County rapidly increasing, NCC announced its plans to build a new Monroe Campus. NCC has committed to build a state-of-the-art, environmentally-friendly facility that will be located on a 72-acre tract of land, situated in the geographic center of Monroe County, near both Route 715 and Route 80. When complete, NCC's new campus will provide educational classes and courses for almost 5,000 students and will also offer training programs for area businesses and industries. The campus will also serve as a meeting space for the community.

To date, the new campus is in the final design stage and site work is tentatively scheduled to begin next fall. The campus is slated to begin offering classes in the fall of 2011. The estimated \$72 million project has the support of state legislators and local officials as well as local businesses and the Commonwealth of Pennsylvania. NCC has commitments for construction funds from County grants, bonds and gaming host fees, the Pennsylvania

Department of Education, the Pennsylvania Department of Community and Economic Development and alumni/private donations.

For fiscal year 2010, I am respectfully requesting \$3.5 million that would allow the Northampton Community College to purchase technology equipment for classrooms at the new Monroe County Campus.

Finally, I am requesting funding for the Blue Mountain Health System to acquire a Mini Picture Archiving and Communication System (PACS). The hospitals of the Blue Mountain Health System are regional providers of health care services to the people living in Carbon, Monroe, Lehigh, Northampton and Schuylkill Counties. The member hospitals of the Blue Mountain Health System have been serving the community for more than 150 years. Each hospital is accredited by the Joint Commission and its diagnostic outpatient services, including vascular testing, mammography, ultrasound, cardiac rehabilitation and clinical laboratory are also accredited by their respective national professional organizations.

Following the call of President Obama to implement an electronic medical record system, Blue Mountain Health System has dedicated part of its yearly fundraising and reserve revenue to the acquisition of a PACS system. PACS is a computer network dedicated to the storage, retrieval, transmission and presentation of medical images. This new system will replace the need for hard copies of medical imaging and decrease the cost of digital storage. Furthermore, due to its computer networking capabilities, the PACS system will help Blue Mountain Health System work with surrounding health care providers to share medical information so that patients do not have to travel for unnecessary tests at other facilities.

For fiscal year 2010, I am respectfully requesting \$300,000 that would allow Blue Mountain Health System, Inc. to purchase a Mini Picture Archiving and Communication System for its imaging departments at its two hospitals located in Carbon County.

In closing, I would like to thank all Members of the Subcommittee for allowing me to provide additional information about several important projects in my Congressional District. I look forward to working you as the House considers appropriations for fiscal year 2010.

Testimony of Congressman Ron Klein to the Subcommittee on Labor, Health and Human  
Services and Education Appropriations

Thank you Chairman Obey, Ranking Member Tiahrt and members of the subcommittee for allowing me to testify today on several priorities that I believe merit robust federal investment. During these tough economic times, our commitment to helping Americans in need is more important than ever.

**MEDICAL RESEARCH**

I am requesting an increase of at least 7% in funding for the National Institutes of Health (NIH) in Fiscal Year 2010. As the primary federal agency for conducting medical research, the NIH has helped lead the way toward important medical discoveries that have transformed the practice of medicine. Composed of 27 institutes and centers, the NIH supports biomedical research efforts in all 50 states and throughout the world to address some of the most debilitating human diseases.

The research conducted by NIH scientists and non federal scientists using NIH grant money has lead to groundbreaking discoveries in the way we treat, prevent and cure diseases such as Parkinson's, cancer, and tuberculosis. NIH research has also proven critical in containing soaring medical costs that affect the viability of our nation's healthcare system. By learning how to contain or prevent illnesses such as diabetes and heart disease, we can reduce a substantial portion of projected health care spending that comes from managing chronic disease.

It is clear that research and technological progress can help save lives and advance our country's priorities. We also know that some of the best scientists, engineers and doctors are working in the most premiere research institutions in the world, right here in the United States. When I served in the Florida State legislature, I helped bring The Scripps Research Institute to Palm Beach County to jumpstart the biotech industry in South Florida. Scripps Florida opened recently, and it couldn't have come at a better time. It is this innovative spirit that makes America strong. When Florida's economy is hurting, jobs in research and technology could help expand employment in our communities.

The NIH has also served as a strong economic driver- producing high wage jobs and generating billions in business activity across the country. Studies indicate that every \$1 million invested by the NIH generates an average of \$2.21 million in new state business activity. Investments in NIH research will help create jobs in every region of the country, make our country more competitive in the biomedical research industry and spur economic growth, all while making a substantial investment in the major health issues of our time.

During my first term in Congress, I had the opportunity to tour the NIH facility in Bethesda, MD. As the nation's largest hospital devoted entirely to clinical research, this facility has the capacity to rapidly transform scientific research into new methods of diagnosis and treatment. The

center conducts over a thousand clinical trials at one time to develop new medications and treatments for diseases that impact millions of Americans. I was amazed by the quality and scale of cutting edge medical research being conducted at this facility, and the aptitude and ingenuity of the NIH researchers.

Over the past several years, however, federal funds for NIH research have not kept pace with the costs of conducting biomedical research. As a result, the NIH has been unable to fund promising new research and clinical trials. The *American Recovery and Reinvestment Act* was an encouraging first step in restoring our commitment to medical research here in the United States, however we must sustain this investment after the ARRA funds expire. A 7% increase in federal funding for FY2010 would put us back on track to become a global leader in the biomedical industry.

#### **COMMUNITY SERVICE**

As a strong advocate for community service and expanding service opportunities for all Americans, I support the President's budget request to increase funds for the Corporation for National and Community Service (the Corporation) by \$261 million in Fiscal Year 2010. One of the defining characteristics of Americans is our commitment to serving others in times of need. The Corporation has helped cultivate this commitment by offering Americans of all ages and backgrounds the opportunity to address some of our community's most pressing problems through service programs such as AmeriCorps, Senior Corps and Learn and Serve. Through these programs, the Corporation provides support in the form of grants and human capital to local service programs that address specific community needs, which may include food drives, clean up efforts and other humanitarian assistance after a natural disaster, tutoring and mentoring services for at risk youth, and assistance for Americans living in poverty. The opportunities are vast and provide Americans with the chance to be a part of something bigger than themselves.

Since its inception, the Corporation has helped log over 1 billion hours in community service through the Senior Corps program, recruited over 400,000 volunteers for service with AmeriCorps and over 1 million high school students each year for service learning initiatives with the Learn and Serve program. Despite declining federal funds, the Corporation has mobilized millions of additional volunteers each year and surpassed their goals for service to the most vulnerable American populations, including disadvantaged youth and elderly Americans living independently.

Following the hurricanes that plagued my home state of Florida, I witnessed firsthand the overwhelming response from volunteers who came out to respond to the needs of hurricane victims. Volunteers came together to provide these victims with clothing, food, shelter, and other items that displaced residents and families needed to get their lives back on track. Since 2005, more than 35,000 AmeriCorps, VISTA, National Civilian Community Corps, Senior Corps and Learn and Serve volunteers have contributed their time and effort to clearing debris, operating shelters, and rebuilding homes for victims of hurricanes in Florida.

The service initiatives enabled by these programs have produced substantial benefits in our communities. Studies indicate that for every dollar spent on service initiatives, we see four dollars of direct, tangible economic returns in our community; and communities with higher numbers of volunteers benefit from higher rates of homeownership, lower poverty rates and higher rates of high school graduation than those communities with fewer volunteers. Volunteer service programs like AmeriCorps also encourage more Americans to pursue careers in public service and continue to engage in community service activities later in life. Over sixty percent of AmeriCorps State and National volunteers go on to work for a nonprofit or governmental organization, and nearly half pursue careers in specific fields such as education, social work, public safety, or military service.

With the enactment of the *Serve America Act* in Congress, we have set the course to significantly expand the number of service opportunities for Americans across the country. At a time of considerable economic uncertainty, this legislation facilitates greater participation in service programs that reach the neediest Americans and meet critical public challenges, such as unemployment, increased homelessness, lack of healthcare coverage and rising high school drop out rates. Specifically, it will triple the number of service opportunities through AmeriCorps, increase education awards for volunteers that dedicate a certain number of hours to service, and establish service opportunities to address current public needs such as healthcare, education, clean energy and services for veterans. I was proud to support this legislation and offer an amendment to allow Veterans Corps volunteers to assist veterans with the cumbersome process of filing benefits claims for disability compensation, healthcare, vocational rehabilitation and any other benefits they qualify for as a U.S. veteran. With thousands of veterans coming home from Iraq and Afghanistan, these services will prove critical in ensuring our vets return home to a life of prosperity.

The President's budget request would put us on track toward tripling the number of service opportunities through the Corporation, from 75,000 to 250,000. By investing in recruitment efforts, increased education awards and grants for new and operating service programs, we can realistically expand our current volunteer roster to 250,000 volunteers. This additional funding would also provide needed resources to strengthen the ability of the Corporation to manage its programs, measure performance, and conduct thorough evaluations of the impact of their programs.

#### **SENIORS' SERVICES**

As you know, South Florida is home to many seniors, and federal assistance to seniors has always been a top priority. The Older Americans Act programs are the cornerstone of the nation's long-term care system, providing older adults with critical services that include home care, home-delivered meals (Meals On Wheels), adult day care, legal services, transportation and caregiver support. Without these services, over 8 million older adults every year would need more expensive institutional care or suffer from hunger, isolation, poor health, neglect, abuse, unemployment or other challenges to their quality of life.



In 2006, the OAA was reauthorized to better meet Congress's vision of offering people greater choice, control and independence by modernizing our long-term care system. Unfortunately, appropriate funding has not followed. Since FY 2004, OAA appropriations have failed to keep pace with growth in inflation and the aging population, leading to a more than \$800 million shortfall.

Yet the need for OAA programs among older adults and caregivers cannot be greater during these difficult economic times. There are now more than 37 million Americans over the age of 65, or 12.6% of the total U.S. population. As additional seniors and caregivers face financial troubles, more will come to need the bedrock programs created by the OAA. Furthermore, investing in OAA programs will save taxpayer dollars by reducing premature or costly Medicaid and Medicare expenditures as a result of unnecessary nursing home placement or poor management of nutrition and chronic health conditions.

To offset the shortfall of over \$800 million that has developed since FY 2004 and to address the pressures of population growth and inflation, I am requesting a 12% increase over FY 2009 for all line items in the Older Americans Act. While I understand the difficult fiscal constraints under which you are operating, I believe this is a necessary investment in the OAA.

I would like to thank you in advance for your consideration of my requests. Though we face many challenges ahead, I'm confident that we can find effective solutions to help American families and those most in need to find prosperity in these tough economic times. By investing in these federal programs, we can make a substantial impact on the quality of life of some of the most vulnerable American citizens.

STATEMENTS FROM  
PUBLIC WITNESSES ON  
FISCAL YEAR 2010  
BUDGET

**Statement of Patricia Harrison  
President and CEO, Corporation for Public Broadcasting  
(202) 879-9662 or [pharrison@cpb.org](mailto:pharrison@cpb.org)  
Before the Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies, U.S. House Committee on Appropriations  
May 1, 2009**

Chairman Obey, Ranking Member Tiahrt, and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of our nation's public service media system.

For more than 40 years, America has relied on public broadcasting for timely information, news, public affairs and unrivaled educational and cultural programming and services. This has been made possible by an investment by the federal government, as well as by a commitment from individuals, corporations, foundations, states and local communities who recognize the value of a robust public broadcasting system to America's civil society.

As the economic situation has deteriorated, and the rest of the media industry contracts, people are turning to public service media with increasing urgency – television, radio, online and beyond the broadcast – because we are a trusted source of news and information and a safe place for kids. Our stations are local, based in communities across our country where they are a valuable information source, connector and partner. However, it is clear that budget cutbacks and layoffs have left many stations struggling to provide the services and programming their communities have come to rely upon and, as a result, this 40 year public-private partnership is now in jeopardy.

As you know, the Corporation for Public Broadcasting (CPB) is a private, nonprofit corporation created by the Public Broadcasting Act of 1967. We are the steward of the federal government's investment in public broadcasting – also known as “public service media.” Because we are the designated entity that receives and distributes the federal investment for public service media, as well the one directly accountable to Congress, I want to inform you of the extraordinary situation facing public broadcasting stations as a result of the economic downturn, as well as some ways in which we are responding.

At a time when we are needed as never before, all of public service media – from local stations to national organizations – is struggling to deal with the impact of a deteriorating economy on various funding streams, including state and university funding, foundation support, pledge and membership, and corporate support. These non-federal sources comprise nearly 85 percent of funding for public broadcasting, so declines in these revenue sources threaten the sustainability of public broadcasting stations across our country and the services they provide to the American people. Despite these financial challenges, the stations themselves are working every day to maintain critical services while responding to increased community need generated by the economic crisis.

CPB is working closely with the leadership of public broadcasting's national organizations, including the Public Broadcasting Service (PBS), National Public Radio (NPR) and the Association of Public Television Stations (APTS), as well as representatives from public radio and television groups, to assess the financial challenge confronting public service media, and to develop the most effective responses. Based on our review of recent surveys conducted by APTS and NPR, public broadcasting stations are, to date, facing a \$307 million revenue loss.

CPB is also developing a new framework and set of principles to guide our work in assisting stations whose operations may be placed in peril due to the economy. CPB's highest priority is maintaining universal service, as enshrined in the Public Broadcasting Act of 1967, which is free access to public television and radio services to every citizen across our country. While CPB's discretionary funds are quite limited, our goal is to do everything we can to ensure no American loses service resulting from a local station having to turn off their transmitter. We are exploring ways to offer counsel and appropriate assistance to stations when and where possible. We are also in discussions with the public broadcasting system about ways to encourage collaboration, efficiencies, joint operations and the adoption of new technologies where appropriate.

In the face of the economic crisis, public service media is still on the ground, providing essential services to communities across our country. Accordingly, in those areas of our formula where we are given direction to fund programming and innovation, CPB has developed a multi-faceted "Public Service Media Economic Response Initiative." This targeted grant program will offer stations ways to enhance service to their communities with a specific focus on the economy.

At the same time, we are reevaluating our priorities within CPB in order to ensure that our limited resources achieve maximum system benefit by fortifying those areas within CPB that most benefit public broadcasting stations on the front-line of service to the American people. As our country continues to address the many challenges presented by the economy, public service media is working hard as a valued partner and a trusted source of information. We must make sure these services continue.

Against the backdrop of the economic situation, the work of public service media continues. In a world of shifting demographics and fast-paced technological change, the concepts of inclusion and innovation are business imperatives.

The Public Broadcasting Act directs CPB to encourage the development of programming that involves creative risk and that addresses the needs of unserved and underserved audiences, particularly children and minorities. CPB seeks to meet the needs of unserved and underserved audiences in a variety of ways, including funding development and production of programming for diverse audiences directly and through the Minority Consortia for television, as well as similar organizations for public radio such as Native Public Media. CPB funds training and professional development for producers and other public media professionals, and supports organizations devoted to meeting the needs of unserved and underserved audiences by assisting with planning, organizational

development, service development, collaboration, and in other ways. In this vein, we have recently announced the hiring of a new senior vice president for Diversity and Innovation who will strengthen the Corporation's capacity to serve as a catalyst for innovation and inclusion within public media and broaden the reach and diversity of our audience. We believe the end result of these initiatives will be a strengthened public service media on both the local and national level.

If all of public broadcasting's activities have a common theme, it is that they are focused on lifelong learning – both formal and informal. In the area of formal education, public media provides services that help in the education of pre-school and young children and help adult Americans obtain their GEDs or earn college diplomas. Education at all levels is the DNA of public media. Many stations have strategic partnerships with their state education agencies and local school districts. These partnerships provide on air, online and in-person community based resources to help teachers and students, parents and caregivers close achievement gaps between higher and lower performing students and increase educational attainment for people of all ages. Investment in public media is a key national strategy to educate *all* of our children and prepare citizens for the global economy.

#### CPB's Request for Appropriations:

Public broadcasting, radio and television, is a national treasure worthy of federal investment. For \$1.54 per American per year, public broadcasting serves as America's community connection. By leveraging \$2.3 billion in non-federal funds, public broadcasting brings the neighborhood to us, not only our own, but the myriad neighborhoods that comprise our great country.

#### *CPB Base Appropriation (FY 2012)*

CPB requests a \$542 million advance appropriation for Fiscal Year (FY) 2012, a 12 percent increase over our request for FY 2011. This request is based on an updated assessment of the financial need of public broadcasting that Booz Allen Hamilton completed for CPB in 2007. Using newly submitted station financial information, the update showed that the public broadcasting system would see an overall deficit beginning in FY 2011, and local stations' plans for expanding services to their communities would require significant increases in both CPB's appropriation and other funding sources to become reality. Staying ahead of the curve and expanding services would total approximately \$3.4 billion in FY 2012. Federal support for public broadcasting (via the CPB appropriation) currently amounts to about 16 percent of public broadcasting's revenues. On this basis, we are requesting an FY 2012 appropriation of \$542 million.

#### *Emergency Station Grants*

CPB is also requesting \$307 million in FY 2010 for emergency grants to public radio and television stations to help them preserve their service to communities across the country during this time of economic crisis. The funding, \$211 million of which would go to

public television stations and \$96 million to public radio, is requested as a line item separate from CPB's general appropriation, to be disbursed by CPB to stations in consultation with system representatives. Due to the present economic conditions, access to public media services is at risk in certain communities in our country. Recent financial assessments point to a number of public television stations that are in danger of failing. The federal government has shown over the last 40 years that public service media is a critical part of our nation's fabric, and has invested substantial sums in ensuring its success. We are requesting extraordinary support for an extraordinary, indispensable public service.

As indicated above, APTS and NPR surveyed their memberships this past winter in order to obtain specific information on revenue declines in FY 2009 and projected declines in FY 2010. From that data, APTS is projecting \$189 million in revenue losses this year, and additional costs of \$21.5 million due to the delayed digital television (DTV) transition. Similarly, from their survey data, NPR is projecting \$96 million in revenue decline. The data found losses across all licensee types, with the hardest hit being community licensees, or those not affiliated with a state or local government or university. However, state budget cuts are affecting state station licensees and, as these cuts begin to impact state universities, stations located on these campuses will be affected by loss of university support. The overall revenue loss numbers will likely increase.

#### *Digital Funding*

CPB is requesting \$40 million in FY 2010 for the continuing conversion of stations to the digital environment. While all the public television transmitters and most radio transmitters have been converted, continued funding is needed to convert the approximately 1,500 radio and television translators, which relay the signal to remote areas. CPB is also helping stations and producers develop content and services to exploit public broadcasting's enhanced digital delivery capacity such as "mobile video." This developing technology offers the opportunity to deliver free public broadcasting content to portable, small screen devices. For example, a child riding in a supermarket cart may be able to watch Sesame Street on Dad's iPod, while he completes the weekly shopping. Another important digital service CPB is working to develop is the American Archive, which will digitize, store and make available a treasure trove of public broadcasting content for educational, cultural and entertainment uses.

#### *Public Radio Interconnection Funding*

CPB is requesting \$27 million in FY 2010 as the third and final year of funding for public radio's satellite interconnection replacement project. CPB received \$26.28 million for this activity in FY 2008 and \$26.6 million in FY 2009. The radio interconnection funding is essential to enable the Public Radio Satellite System (PRSS) to maintain its broadcast program delivery services to America's local stations, and support the rapidly expanding needs for content distribution in the digital age. The Public Broadcasting Act charges CPB with providing for the interconnection needs of public television and radio. Since our last request, NPR – which operates PRSS on behalf of public radio entities – has announced plans to move its headquarters, a step which will increase the cost of the overall project by \$6.2 million.

*Ready To Learn*

CPB is requesting \$32 million in FY 2010 for Ready To Learn (RTL), a Department of Education program that is using the power and reach of public television's children's programming that is achieving measurable results in raising the reading levels of children ages 2-8 who live in high-poverty environments. Ready To Learn is a partnership between CPB and PBS, WGBH (Boston), WTTW (Chicago), Sesame Workshop, Out of the Blue Productions, leading researchers on reading, and public television stations nationwide. An appropriation of \$32 million in FY 2010 will enable RTL content and accompanying materials to be created and tested on a faster timeline, and will enable more communities to become involved in station-based outreach activities.

Mr. Chairman, thank you again for allowing CPB to submit this testimony to your subcommittee. As we do every year, we will also be submitting a more detailed justification to the subcommittee for the above requests.

For more than 40 years public broadcasting has provided a safe place for millions of children to learn; it has provided unparalleled access to news and information; given voice to diverse points of view; and convened community dialogues. As the times have changed, so too have the technologies available for public media to provide service to communities across our country. The challenge before us is how best to incorporate new capabilities into the public interest and service for all of our diverse citizenry, especially during these challenging economic times. With the support of Congress, we are ready to meet this challenge.

Thank you.

**RAILROAD RETIREMENT BOARD  
FISCAL YEAR 2010 BUDGET REQUEST**

**Statement for the Record, May 15, 2009**

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH  
AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES**

**Michael S. Schwartz, Chairman of the Board**

**V. M. Speakman, Jr., Labor Member of the Board**

**Jerome F. Kever, Management Member of the Board**

Mr. Chairman and Members of the Committee:

We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2010 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. During fiscal year 2008, the RRB paid \$10.1 billion in retirement/survivor benefits and vested dual benefits to about 598,000 beneficiaries. We also paid \$80 million in net unemployment/sickness insurance benefits to about 30,000 claimants.

**PROPOSED FUNDING FOR AGENCY ADMINISTRATION**

The President's proposed budget would provide \$109,073,000 for agency operations, which would enable us to maintain a staffing level of 920 full-time equivalent staff years (FTEs) in 2010. The proposed budget would also provide about \$1,651,000 for information technology (IT) investments. This includes \$615,000 for costs related to information security and privacy, and for continuity of operations in the event of an emergency. The remaining IT funds will be used for E-Government initiatives, systems modernization, infrastructure needs and system support.

**AGENCY STAFFING**

The agency's dedicated, experienced employees have been the foundation for our tradition of excellence in customer service and satisfaction. And, we have an ongoing need and responsibility to effectively manage our human capital resources. This is particularly important given the number of RRB employees who are eligible for retirement and those who soon will be. We are developing a long-range approach to workforce planning that will position the agency for continued success in administering our programs. This includes a detailed analysis of the



demographic features of the RRB workforce and the skills needed to fulfill our mission. It will also establish a procedural framework for recruiting, training and developing talented employees.

Like many agencies, the RRB has an aging workforce. About 30 percent of our workforce is currently eligible to retire, and over 50 percent will be eligible by fiscal year 2012. In response to this trend, we have placed added emphasis on filling entry-level positions, focusing on front-line service employees and claims examiners to the extent possible. In anticipation of an increase in the agency attrition rate as more employees become eligible to retire, these new employees will be key to effectively administering the RRB's programs and continuing to provide excellent service over the long term.

### **SERVICE IMPROVEMENTS**

In fiscal year 2009, we have implemented nationwide toll-free telephone service, which enables us to dynamically route phone calls among our offices based on logical business rules and customer needs. In addition to providing our customers with faster response times, the toll-free service allows agency management to more effectively balance and share workloads among offices. We plan to continue expanding the functionality and services offered through the toll-free number (1-877-772-5772 or 1-877-RRB-5RRB). Enhancements will focus on new self-service options available through the toll-free system.

The RRB's long-term information technology strategy also calls for expanded use of the Internet to provide services to our customers. We plan to use contractor services to augment agency staff to expand the electronic services available to the railroad public via the RRB's website. As part of this strategy, we are continuing to work on the Employer Reporting System (ERS) to increase the amount of information related to railroad compensation, employment and service that employers can transmit to the RRB through the Internet. In fiscal year 2010, we plan to expand services to provide additional notifications to rail employers and enable employers to correct data through the system.

### **SYSTEMS MODERNIZATION**

Over the last few years, we have undertaken a series of strategic measures to improve computer processes and better position the RRB for the future. First, the agency moved to a relational database environment, and then optimized the data that reside in the legacy databases. Our next steps involve modernizing the agency's computer processes.

Many of the RRB's existing systems are old, complex, and require a large investment in maintenance. As projected staff attrition occurs, we will be losing both experienced technical staff and some of the business subject matter experts who now support our legacy systems. The modernization process will enable us to maintain the capability of our business function in the face of expected staff turnover, and to upgrade our systems based on the improvements that we have already completed. Through these initiatives, we will eliminate or reduce unnecessary or redundant activities, improve the accuracy and security of our systems and their transactions, make the systems more user-friendly for agency employees and our customers, improve the interoperability and flexibility of systems, and improve the RRB's ability to collaborate with

agency partners. These improvements will ultimately decrease the time and cost to develop and operate RRB systems and allow an increased focus on new initiatives.

We plan to begin this process in fiscal year 2009, with selection of the agency's first system to modernize and development of a project plan. The selected system will serve as a pilot for further modernization. In fiscal year 2010, we will use contractor services to evaluate the pilot project's business requirements, identify possible solutions, analyze them and recommend one for implementation.

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The President's proposed budget includes \$64 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$1,280,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits."

In addition to the requests noted above, the President's proposed budget includes \$150,000 for interest related to uncashed railroad retirement checks.

#### **FINANCIAL STATUS OF THE TRUST FUNDS**

**Railroad Retirement Accounts** –The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The market value of Trust-managed assets on September 30, 2008, was approximately \$25.3 billion. Trust-managed assets have declined as a result of the general economic downturn in 2008 and the early part of 2009. The Trust reported that Trust-managed assets amounted to \$19.1 billion as of March 31, 2009. The Trust has transferred to the Railroad Retirement Board for payment of railroad retirement benefits approximately \$7.3 billion since the inception of the Trust.

In June 2008, we released the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report, which reflects changes in benefit and financing provisions under the Railroad Retirement and Survivors' Improvement Act of 2001, addressed the 25-year period 2008-2032 and contained generally favorable information concerning railroad retirement financing. The report included projections of the status of the retirement trust funds under three employment assumptions. These indicated that, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system would experience no cash flow problems throughout the projection period. Our next report, which will be released in June 2009, will include updated projections reflecting the economic events of the past year.

**Railroad Unemployment Insurance Account** – The equity balance of the Railroad Unemployment Insurance Account at the end of fiscal year 2008 was \$99.9 million, a decrease of \$0.8 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2008. The report indicated that even as maximum daily benefit rates rise 47 percent (from \$59 to \$87) from 2007 to 2018, experience-based contribution rates maintain solvency. The report did not recommend any financing changes. We will update this analysis in our next annual report on the system, which will be released in June 2009.

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In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

STATEMENTS FROM  
RELATED AGENCIES ON  
FISCAL YEAR 2010  
BUDGET



**House Appropriations Subcommittee on Labor, Health and Human Services (HHS),  
Education, and Related Agencies**

**Hearing on “Pathway to Health Reform: Implementing the National Strategy  
to Reduce Healthcare-Associated Infections”**

**April 1, 2009**

**Submitted for the Record by 3M Company**

3M Company (“3M”) appreciates the opportunity to provide written comments for the record for this hearing and commends the Subcommittee for focusing on this important issue.

3M, a United States-based employer and manufacturer, was established over a century ago in Minnesota. While 3M initially began by developing sandpaper products, 3M is now one of the largest and most diversified technology and manufacturing companies in the world. 3M is home to such well-known brands as Scotch, Post-it, Nexcare, Command, and Thinsulate and is composed of six business sectors: Consumer and Office; Display and Graphics; Electro and Communications; Health Care; Industrial and Transportation; and Safety, Security and Protection Services.

3M’s founders insisted on a robust investment in R&D. Today, 3M maintains more than 40 different technology platforms which allow 3M scientists to share and combine technologies from one business to another, creating unique, innovative solutions for its customers. The financial commitment to R&D equated to \$1.4 billion of R&D spending in 2007 and a total of \$6.6 billion during the past five years, and produced high quality jobs for 3900 researchers in the U.S. (and 7000 total worldwide). The results are equally impressive with 571 U.S. patents awarded in 2007 alone, and over 40,000 global patents and patent applications. 3M has operations in 27 U.S. states, where over 60% of 3M’s worldwide manufacturing operations are located and over 60% of its worldwide R&D activities are conducted.

**3M Health Care: Solutions to Infections**

For more than 30 years, 3M Health Care has pioneered infection prevention solutions designed to stall the spread of pathogenic viruses and bacteria at the point of care and beyond. 3M Health Care is uniquely able to draw on the full breadth of 3M innovative technologies, making us a highly effective partner to the health care provider in addressing healthcare associated infection (HAI) and healthcare associated condition (HAC) reductions. In addition, 3M’s operational excellence strategies, including Six Sigma improvement methodologies and quality management systems, directly align to the process improvements needed to reduce HAIs and HACs.

3M Health Care believes that the health care industry has shared responsibility with government and consumers for the national prevention of HAIs and HACs. 3M Health Care has developed a wide range of solutions that help professional health care providers detect, prevent and control HAIs and HACs. These products are successfully used to fight many of the major

classes of HAIs, such as Surgical Site Infections (SSI), Central Line Associated Blood Stream Infections (CLABSI), Ventilator Associated Pneumonia (VAP) and horizontal spread of infections within a healthcare facility. 3M Health Care's innovative solutions include:

- 3M™ Surgical clippers, 3M™ DuraPrep™ surgical solution, 3M™ Ioban™ antimicrobial incise drapes, 3M™ SteriStrip™ S surgical skin closure system and 3M™ Tegaderm™ dressings provides a complete system for controlling the risks of SSIs;
- 3M's full barrier protection products (surgical drapes and masks) combined with skin preps and the Tegaderm™ CHG (chlorhexidine gluconate) IV securement dressings are among the solutions for addressing CLABSI;
- Peridex™ CHG Oral rinse is a key part of oral care protocols that have been shown to help reduce the risk of VAP;
- A complete line including 3M™ Avagard™ hand hygiene products and 3M™ Clean-Trace™ rapid environmental diagnostics help to detect and prevent the risk of transmission of infectious agents (horizontal spread);
- Tegaderm CHG dressing enhances current IV site protection efforts by working in conjunction with skin preparation protocols. The unique properties of the gel pad, combined with the antimicrobial qualities of CHG, create an easy-to-apply technology that provides ongoing antimicrobial activity at the insertion site. Tegaderm CHG: Chlorhexidine Gluconate I.V. Securement Dressing containing 2% w/w CHG;
- 3M sterilization assurance products such as Attest™ biological monitors to ensure successful medical instrument sterilization to products used in procedures; and
- 3M Health Information Systems (HIS) provides coding and data analysis support, facility-wide, for monitoring costs and reimbursements.

#### **HHS Action Plan to Prevent HAIs**

3M Health Care strongly supports the HHS *Action Plan to Prevent Healthcare-Associated Infections*(HAIs), which establishes positive steps toward improving patient care through the reduction of HAIs. 3M Health Care is committed to providing products, services, and education focused on the detection, prevention, and control of HAIs. We provided comments to the plan in the spirit of partnership in working toward this important goal. Highlights of our comments include:

- Important tools used within industry, such as application of a quality management system (QMS) and six sigma tools, are applicable within the healthcare industry and could help support the goal of HAI and HAC reduction;
- Multicenter collaborative trials should be conducted to establish the efficacy of preventive interventions;
- Many innovative technologies are comprised of already approved safe and effective device and antiseptic drugs (i.e.: antiseptic impregnated surgical drapes and antimicrobial securement dressings). HHS makes reference to infection rate studies being conducted, based on such "bundled" or combination products. 3M agrees with this

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approach and asks HHS to consider the risk versus benefit profile of these combination products so as not to discourage this type of product development.

- The importance of hand hygiene compliance must be emphasized. 3M Health Care strongly encourages HHS to establish a metric and target around hand hygiene compliance which would have positive impact on decreasing all target HAI types.

#### **Improving Patient Outcomes and Reducing Medicare Costs**

In 2000, the CDC estimated that HAIs add almost \$5 billion to U.S. healthcare costs annually. A *Public Health Reports* study in 2007 stated that in 2002, 1.7 million HAIs were associated with nearly 99,000 deaths. Congress began to address this in the Deficit Reduction Act (DRA) with a provision to cut the additional Medicare hospital payment for certain patient cases including HAIs. While a good start, these changes have only impacted less than one half of one percent of Medicare spending. In addition to HAIs, the overall patient hospitalization is often marked by inconsistent attention to what happens to the patient during the hospitalization, at discharge or over the following weeks. According to MedPAC, 18% of Medicare hospital admissions result in readmissions within 30 days, costing \$15 billion dollars – with nearly \$12 billion of those estimated to be potentially preventable.

As recommended by MedPAC last June, Congress should align incentives among providers through such things as confidential and public reporting for hospitals on a set of defined group of potentially preventable HACs and readmissions and payment incentives for hospitals to reduce risk-adjusted HAC readmission rates for selected, potentially preventable conditions. Taking steps in Medicare to promote better outcomes will not only drive quality, but also reduce costs. It will improve patient care coordination and foster greater dialogue between hospitals and physicians on how to find more efficient ways to deliver higher quality care.

A number of states have already begun to take steps on HACs and readmissions. For example: New York has been providing hospitals with confidential reporting on HACs for 3 years; Florida began publicly reporting hospital readmission rates in July 2008 on the internet at <http://www.floridahealthfinder.gov/CompareCare/SelectChoice.aspx>; and Maryland is in the process of implementing payment readjustment for preventable hospital complications that go into effect in 2009.

#### **Conclusion**

We thank the Committee for the opportunity to share our perspective on how to reduce the prevalence of HAIs. 3M stands prepared to work with you in any way we can to support you on this critical public policy matter.

Advocate Health Care  
 Written Testimony to the House Labor-Health and Human Services (LHHS)  
 Appropriations Subcommittee  
 Regarding Fiscal Year 2010 Title VII and Title VIII Funding  
 Submitted by: Jim H. Skogsbergh  
 Phone: (630) 990-5008  
 EM: [Jimskogsbergh@advocatehealth.com](mailto:Jimskogsbergh@advocatehealth.com)

May 1, 2009

### **Introduction and Overview**

Advocate Health Care (Advocate) – the largest integrated health care provider in Illinois – very much appreciates the opportunity to submit written testimony for the record regarding federal funding for the Title VII and Title VIII programs of the Public Health Service Act. Advocate serves 3.1 million patients annually and has a presence in virtually every Illinois Congressional district through the operation of more than 200 sites of care. Specifically, nine acute care hospitals, two children’s hospitals, four Level I trauma centers (the state’s highest designation in trauma care), a home health care company, and the region’s largest medical group – in Illinois’ 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>, 4<sup>th</sup>, 5<sup>th</sup>, 6<sup>th</sup>, 7<sup>th</sup>, 8<sup>th</sup>, 9<sup>th</sup>, 10<sup>th</sup>, 13<sup>th</sup> and 14<sup>th</sup> Congressional districts. Advocate also serves patients from – and employs people in the 11<sup>th</sup> and 16<sup>th</sup> Congressional districts of Illinois. As the second largest employer in the Chicagoland area, Advocate employs 28,000 individuals, including 7,000 nurses. More than 5,000 physicians are also affiliated with Advocate.

Advocate maintains a long-standing commitment to supporting the nurses who work within the Advocate system and to increasing resources at the state and federal level to bolster and expand Illinois’ and the nation’s nursing workforce. High-quality, compassionate health professionals are critical to the delivery of care in the Advocate system. Without our 7,000 nurses – who work hard every day on behalf of patients and their families, our standard of care could not be achieved for the millions of people we serve throughout Illinois each year.

Advocate joins with Members of Congress, national nursing organizations, health professional societies and coalitions, and the general public in being deeply concerned about the current and anticipated national shortages of nurses and other health professionals and their potential adverse impact on patient access to quality care. To that end, Advocate respectfully urges the House Labor-Health and Human Services-Education Appropriations Subcommittee to provide \$550 million in FY 2010 funding for the Title VII and Title VIII programs of the Public Health Service Act to support and expand diversity within the nation’s health care workforce, and ensure that the nation has the nurses and other health professionals it needs to provide quality care to the patients of today and tomorrow.

### **The Nursing Shortage and the Need for Title VIII Funding**

According to an April 13, 2009 Wall Street Journal article, last summer, the nation was short approximately 125,000 nurses. The nurse faculty shortage is of serious concern, since it is widely-recognized as a principal cause of the nursing shortage. The American Association of



Colleges of Nursing reports that in 2008, nearly 50,000 qualified applicants were not able to matriculate in nursing school, “due primarily to a shortage of faculty shortage and resource constraints.” Although the recent economic downturn has prompted some nurses, who were retired or otherwise not working, to return to the workforce, many communities across the nation still do not have enough nurses to work in their hospitals and nursing homes, or to provide care in home or ambulatory settings.

The Health Resources and Services Administration (HRSA) estimates that, due to a combination of increased demand and the anticipated insufficient supply of registered nurses, the nation will face a growing shortage in the years ahead. Specifically, the nation will be short an estimated 275,215 nurses in 2015 – a deficit that will grow to approximately 808,416 by 2020. Within Illinois, HRSA predicts that the state will be short an estimated 9,300 nurses in 2010 and 31,900 in 2020. Since nearly 60 percent of all nurses are employed by hospitals, the national and state level nursing shortages will have a significant and disproportionate impact on hospitals and hospital systems, including Advocate.

The Title VIII Nursing Workforce Development Programs, housed at HRSA, provide resources to support the education and training for entry-level and advanced practice nurses. Specifically, Title VIII programs offer loans, scholarships, traineeships, and other support to tens of thousands of individuals each year. According to the Health Professions and Nursing Education Coalition (HPNEC), more than 50,000 nursing students and nurses received support from Title VIII in FY 2008. However, it is important to note that the demand for such financial support far exceeds current resources. In FY 2008, HRSA received 6,078 applications for the Nurse Education Loan Repayment Program, but only had the funds to award 435 of those applications.<sup>1</sup> Also, in FY 2008, HRSA received 4,894 applications for the Nursing Scholarship Program, but only had funding to support 172 awards.<sup>2</sup> As such, to ensure that the nation can educate, train, and deploy enough nurses to the communities most in need, Advocate urges the Subcommittee to provide a significant increase to Title VIII programs in FY 2010.

#### **Physician Shortages and the Need for Title VII Funding**

The Title VII health professions programs, housed within HRSA, provide: loans, loan guarantees and repayments, and scholarships to students; and contracts and grants to non-profit organizations and entities, as well as academic institutions. Program funding supports: (1) health professional training – with a focus on increasing minority representation in the health care workforce, and (2) myriad community-based programs, which seek to increase access to care for underserved individuals and communities in Illinois and across the nation. As the nation

<sup>1</sup> U.S. Health Resources and Services Administration: Nurse Education Loan Repayment Program: <http://bhpr.hrsa.gov/nursing/loanrepay.htm>. Accessed April 22, 2009.

<sup>2</sup> U.S. Health Resources and Services Administration: Nursing Scholarship Program Statistics: <http://bhpr.hrsa.gov/nursing/scholarship/>. Accessed April 22, 2009.

*Advocate Health Care  
FY 2010 Written Testimony Submitted to the  
House LHHS Appropriations Subcommittee  
May 1, 2009*

currently faces shortages of primary care and specialty physicians – shortfalls that are expected to worsen in the coming years – these programs play a critical role in bolstering the nation’s health workforce and helping to ensure its diversity.

Advocate is proud that from FY 2003 to FY 2006, Advocate Illinois Masonic Medical Center (AIMMC) – an urban, Level I trauma center serving primarily high-risk populations in medically underserved and ethnically diverse Chicago northside communities – received a total of more than \$600,000 in funding from HRSA for its two residency programs – in family practice and dentistry. HRSA funding helped support the training of 23 primary care/family practice residents, approximately 40 percent of whom were ethnic minorities. This federal funding of the AIMMC residency program helped develop dozens of physicians who chose to practice in primary care, many of whom specifically work in underserved communities. For example, graduates of the AIMMC family residency program have gone on to practice in rural health clinics, Federally Qualified Health Centers, federal and state Health Professional Shortage Areas, the Indian Health Service, and HIV/AIDS primary care clinics. In addition, past HRSA funding also supported the AIMMC dental residency program, allowing the staffing of a mobile dental van that provides care to approximately 600 individuals – primarily uninsured – who have limited access to dental providers and care.

As you know, funding for the Title VII programs was reduced by more than 50 percent from FY 2005 to FY 2006, and funding for the Title VIII program was decreased by nearly 34 percent during the same period. Due to these significant cuts – coupled with modest increases in the subsequent years – there have not been adequate resources to continue to fund Advocate’s residency programs. The lack of Title VII and Title VIII funding has had a significant impact on our – and other hospitals’ – ability to train the next generation of physicians and dentists. Moreover, we are concerned that the nation is not investing adequately in health professionals who have an interest in – and commitment to – working in underserved communities. Increased FY 2010 funding for Title VII will help ensure that our nation is making the investment necessary to have the educated, well-trained, and diverse health professional workforce to care for a growing population in need.

#### **FY 2010 Funding Request and Conclusion**

As the Congress works to increase access to health care for all Americans – a critical action we support – the number of individuals seeking care is anticipated to grow significantly. At the exact same time that demand for health care likely will rise, the nation is facing a significant shortage of nurses, physicians, and other health professionals. Therefore, we urge the Subcommittee to provide \$550 million to the Title VII and Title VIII programs of the Public Health Service Act to bolster the nation’s health workforce and ensure access to care for all in need. We thank the Subcommittee for its consideration of our views and stand ready to be a resource to you on health workforce and other matters.

**FY 2010 Written Testimony for the Labor, Health and Human Services,  
and Education Subcommittee of the House Appropriations Committee**

By Ronald Johnson, Deputy Executive Director, AIDS Action

I am pleased to submit this testimony to the Members of this committee on the importance of increased funding for the Fiscal Year (FY) 2010 HIV/AIDS portfolio. Since 1984, AIDS Action Council, through its member organizations and the greater HIV/AIDS and public health communities, has worked to enhance HIV prevention programs, research protocols, and care and treatment services at the community, state and federal level. AIDS Action represents many AIDS service organizations located in the nation's HIV epicenters, local health departments, smaller service providers, faith-based organizations, substance abuse treatment centers, and education and advocacy organizations from all over the country. AIDS Action's goals are to ensure effective, evidence-based HIV care, treatment, and prevention services; to encourage the continuing pursuit of a cure and a vaccine for HIV infection; and to support the development of a public health system which ensures that its services are available to all those in need. On behalf of AIDS Action Council's diverse membership I bring your attention to issues impacting funding for FY 2010.

Nearly 30 years since it was first identified, the HIV/AIDS epidemic in the United States is characterized by needless mortality, inadequate access to care, persistent levels of new infection, and stark racial inequalities. Despite the good news of improved treatments, which have made it possible for people with HIV disease to lead longer and healthier lives, stark realities remain. Consider that in the United States...

- Every year, 56,300 people are newly infected with HIV – **one new infection every 9 ½ minutes**. According to the Centers for Disease Control and Prevention (CDC) the HIV infection rate has not fallen in 15 years and the new incidence figure represent a 40% increase from previous estimates
- CDC stated that the **HIV incidence rate increased by 15%** from 2006 to 2007.
- Over a million people are living with HIV or AIDS; an **estimated half of people living with HIV/AIDS are not in care**.
- Of those people living with HIV/AIDS **21% are unaware of their HIV status**.
- CDC estimates in 2007, **14,561 people died** from AIDS related causes.
- African Americans represent **13% of the population but nearly half of all newly reported HIV infections**.
- Hispanics/Latinos represent **13% of the population but account for 18% of newly reported cases of HIV**.
- **The percentage of newly reported HIV/AIDS cases in the U.S. among women tripled from 8% to 27% between 1985 and 2007.**
- AIDS is the **leading cause of death among black women aged 25-34**
- HIV is the **#1 health care risk for gay men and men who have sex with men, especially in communities of color**.
- More than **half of all newly diagnosed individuals are identified with full blown AIDS in less than 12 months of their initial diagnosis**.
- There is neither a cure nor a vaccine for HIV and current treatments do not work for everyone.

The federal government's commitment to funding prevention, research, and care and treatment for those living with HIV is critical. We would be unable to respond to this epidemic without the federal government's increased commitment to funding HIV programs at home. However, we are not doing enough. The unsatisfactory outcomes from our country's response to AIDS have serious human and economic costs. A study published in 2003 found that failure to meet the government's then goal of reducing HIV infections by half would lead to \$18 billion in excess expenses through 2010. We need more prevention, more treatment and care and more research if we are ever to slow and eventually reverse the HIV epidemic.

It is AIDS Action's expectation that the Congress, through the good work of this subcommittee, will recognize and address the true funding needs of the programs in the HIV/AIDS portfolio. HIV is a 100% preventable disease that can be lessened with a focused, concentrated effort and increased funding. The community has come together under the umbrella of the AIDS Budget and Appropriations Coalition with the community funding request for the HIV/AIDS domestic portfolio for FY 2010. The numbers requested represent that community work. These requests have been submitted to the committee.

The Centers for Disease Control and Prevention estimate that approximately thirteen percent of all HIV cases and approximately 60 percent of all hepatitis C cases in the United States are directly or indirectly related to intravenous drug use. One of the most important ways to reduce these epidemics is through the use of syringe exchange. More than eight federal studies along with numerous scientific peer reviewed papers published over 15 years have conclusively established that syringe exchange programs reduce the incidence of HIV among people who inject drugs and their sexual partners. Such studies have all concluded that syringe exchange does not increase drug abuse. Instead, syringe exchange programs connect people who use drugs to health care services including addiction treatment, HIV and viral hepatitis prevention services and testing, counseling, education, and support.

The ban on federal funding for syringe exchange is counterproductive and limits the ability of local and state jurisdictions to respond effectively to the twin HIV and hepatitis epidemics. **AIDS Action and the HIV community recommends that the Committee remove any language prohibiting the use of federal funds to establish or carry out a program of distributing sterile syringes to reduce the transmission of blood borne pathogens, including the human immunodeficiency virus (HIV) and viral hepatitis.**

According to CDC estimates contained in the agency's March 2006 HIV/AIDS Surveillance Report, 1,014,797 cumulative cases of AIDS have been diagnosed in the United States, with a total of 565,927 deaths since the beginning of the epidemic. As noted above, the CDC estimates that between 1.1 and 1.2 million people are living with HIV/AIDS and that 250,000 -350,000 people are unaware of their status and could unknowingly transmit the virus to another person. As funding has remained essentially flat for more than eight years, money has shifted to new and needed HIV testing efforts and initiatives. As a result, grants to states and local communities have significantly decreased and new infections have increased to an estimated 56,300 per year, according to a CDC report released in August 2008. **Therefore, AIDS Action Council, the HIV community, and the CDC in their budget justification before Congress September 2008, estimates that the CDC HIV Prevention and Surveillance programs will need \$1.5**

**billion, an increase of \$878 million, in FY 2010 to address the true unmet needs of preventing HIV in the United States.** In the United States, HIV is transmitted primarily through sex. In order to combat the rising rates of transmission, we must ensure that sexuality education programs are medically sound and effective in fostering healthy behavior over the long-term. Abstinence is an important component of comprehensive sexuality education and HIV prevention programs; however, when it is advocated as the only option for young people, research has shown that it is ineffective, unrealistic, and potentially harmful. We believe the federal government should only support those sexuality education and HIV-prevention programs that are evidence-based. For that reason **we support the elimination of all funding for the Community-Based Abstinence Education (CBAE) programs. All such funds should be re-directed to evidence-based prevention and educational programs.** This past World AIDS Day, President Obama affirmed that, "My administration will ...work with Congress to enact an extensive program of prevention, including access to comprehensive age-appropriate sex education for all school age children." **We request that at least \$50 million be allocated to promote comprehensive sex education in our schools and communities nationwide.**

Now in its nineteenth year, The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, administered by the Health Resources and Services Administration (HRSA) and funded by this subcommittee, provides services to more than 533,000 people living with and affected by HIV throughout the United States and its territories. It is the single largest source of federal funding solely focused on the delivery of HIV services; it provides the framework for our national response to the HIV epidemic. CARE Act programs have been critical to reducing the impact of the domestic HIV epidemic. Yet in recent years, CARE Act funding has not kept pace with the epidemic and has decreased through across-the-board rescissions. It is important to remember that CARE Act programs are designed to compliment each other. It is necessary that all parts of the CARE Act receive substantial increased funding to ensure the success of the total program. **AIDS Action and the HIV/AIDS community estimate that the entire Ryan White CARE Act portfolio needs \$2.816 billion in FY 2010, an increase of \$577.8 million to address the true needs of the hundreds of thousands of people living with HIV who are uninsured, underinsured, or who lack financial resource for health care.**

Part A of The Ryan White CARE Act now includes five additional Transitional Grant Areas (TGAs). Some of the services provided under Part A include physician visits, laboratory services, case management, home-based and hospice care, and substance abuse and mental health services. Under the most recent reauthorization these services are even more dedicated towards funding core medical services and to ensuring the ability of patients to adhere to treatment. These services are critical to ensuring patients have access to, and can effectively utilize, life-saving therapies. **AIDS Action along with the HIV/AIDS community recommends funding Part A at \$766.1 million, an increase of \$103 million.**

Part B of the CARE Act ensures a foundation for HIV related health care services in each state and territory, including the critically important AIDS Drug Assistance Program (ADAP). Part B base grants (excluding ADAP) received a decrease of \$28.5 million in FY 2009. **AIDS Action along with the HIV/AIDS community recommends funding for Part B base grants at \$514.2 million, an increase of \$105.4 million.**

The AIDS Drug Assistance Program (ADAP) provides medications for the treatment of individuals with HIV who do not have access to Medicaid or other health insurance. According to the 2009 National ADAP Monitoring Project, ADAP provided medications to approximately 183,299 clients in FY 2007, including 36,354 new clients. **AIDS Action along with the HIV/AIDS community recommends \$1,083 million, an increase of \$268.6 million, for ADAP for FY 2010.** This “community need” number is derived from a pharmacoeconomic model to estimate the amount of funding needed to treat ADAP eligible individuals in upcoming federal and state fiscal years. The need number represents the amount of new funding required to allow state ADAPs to provide a minimum clinical standard formulary of HIV/AIDS medications to ADAP clients under the current eligibility rules for each state.

Part C of the Ryan White CARE Act awards grants to community-based clinics and medical centers, hospitals, public health departments, and universities in 22 states and the District of Columbia under the Early Intervention Services program. These grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic. Part C funds are particularly needed in rural areas where the availability of HIV care and treatment is still relatively new. Urban areas continue to require Part C funds as emerging populations as grantees struggle to meet the needs of previously identified HIV positive populations. **AIDS Action, along with the HIV/AIDS community, requests \$268.3 million, an increase of \$66.4 million, for Part C.**

Part D of the Ryan White CARE Act awards grants under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth, as well as their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families. **AIDS Action and the HIV/AIDS community request \$134.6 million, an increase of \$57.7 million, for Part D.**

Under Part F, the AIDS Education and Training Centers (AETCs) is the training arm of the Ryan White CARE Act; they train the healthcare providers, including the doctors, advanced practice nurses, physicians’ assistants, nurses, oral health professionals, and pharmacists. The role of the AETCs is invaluable in ensuring that such education is available to healthcare providers who are being asked to treat the increasing numbers of HIV positive patients who depend on them for care. Additionally, the AETCs have been tasked with providing training on Hepatitis B and C to CARE Act grantees and to ensure inclusion of culturally competent programs for and about HIV and Native Americans and Alaska Natives. However no funding has been added for additional materials, training of staff, or programs. The AETCs received a modest increase of \$0.3 million in FY 2009. **AIDS Action and the HIV/AIDS community request \$50 million, a \$15.6 million increase, for this program.** Also under Part F, Dental care is another crucial part of the spectrum of services needed by people living with HIV disease. Oral health problems are often one of the first manifestations of HIV disease. Unfortunately oral health is one of the first aspects of health care to be neglected by those who cannot afford, or do not have access to, proper medical care removing an opportunity to catch early infections of HIV. **AIDS Action and the HIV/AIDS community request \$19 million, a \$5.6 million increase, for this program.** Finally under Part F, rising infections and strapped care systems necessitate the research and development of innovative models of care. The SPNS program is designed for this purpose and must continue to receive sufficient funding.

The Minority AIDS Initiative directly benefits racial and ethnic minority communities with grants to provide technical assistance and infrastructure support and strengthen the capacity of minority community based organizations to deliver high-quality HIV health care and supportive services to historically underserved groups. HIV/AIDS in the U.S. continues to disproportionately affect communities of color. According to the CDC in 2006, the overall rate of HIV diagnosis (the number of diagnoses per 100,000 population) in the 33 states (that currently report HIV data) was 18.5 per 100,000. The rate for blacks was roughly 8 times the rate for whites (67.7 per 100,000 vs 8.2 per 100,000). The Minority AIDS Initiative provides services across every service category in the CARE Act and was authorized for inclusion within the CARE Act for the first time in the 2006 CARE Act reauthorization. It additionally funds other programs throughout HHS agencies. **AIDS Action and the HIV/AIDS community request a total of \$610 million for the Minority AIDS Initiative.**

Research on preventing, treating and ultimately curing HIV is vital to the domestic and global control of the disease. It is essential that Office of AIDS Research continue its groundbreaking research in both basic and clinical science to develop a preventative vaccine, microbicides, and other scientific, behavioral, and structural HIV prevention interventions. The United States must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. NIH's Office of AIDS Research is critical in supporting all of these research arenas. Commitment in research will ultimately decrease the care and treatment dollars needed if HIV continues to spread at the current rate. **AIDS Action requests that the National Institutes of Health be funded at \$34 billion in FY 2010 and that the AIDS portfolio must be funded at \$3.4 billion a \$500 million increase.**

HIV is a continuing health crisis in the United States. We must continue to work to fully fund our domestic prevention, treatment and care, and research efforts. On behalf of all HIV positive Americans, and those affected by the disease, AIDS Action Council urges you to increase funding in each of these areas of the domestic HIV/AIDS portfolio. Help us save lives by allocating increased funds to address the HIV epidemic in the United States.

Respectfully submitted,  
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THE AIDS INSTITUTE

May 1, 2009

**WRITTEN STATEMENT OF CARL SCHMID, DIRECTOR OF FEDERAL AFFAIRS,  
THE AIDS INSTITUTE  
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND  
RELATED AGENCIES  
HOUSE COMMITTEE ON APPROPRIATIONS**

Dear Chairman Obey and Members of the Subcommittee:

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the FY2010 Labor, Health and Human Services, Education and Related Agencies appropriation measure. We thank you for your support of these programs over the years, and trust you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

**HIV/AIDS**

HIV/AIDS remains one of the world's worst health pandemics in history. Worldwide, some 33 million people are infected with this incurable infectious disease, and 7,400 new infections occur each day. Tragically, AIDS has already claimed the lives of over 25 million. Here in the U.S., according to the CDC, 583,298 people have died of AIDS. Last year, the CDC announced that its estimate of new infections per year is now 56,300, which is 40 percent higher than previous estimates. That translates into a new infection every 9 ½ minutes. At the end of 2007, an estimated 1.1 million people in the U.S. were living with HIV/AIDS.

Persons of minority races and ethnicities are disproportionately affected by HIV/AIDS. African Americans, who make up 12% of the US population, account for half of the HIV/AIDS cases. HIV/AIDS also disproportionately affects the poor, and about 70 percent of those infected rely on public health care financing.

The U.S. government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically are funded through your Subcommittee. The AIDS Institute, working in coalition with other AIDS organizations, has developed funding request numbers for each of these domestic AIDS programs. We ask that you do your best to adequately fund them at the requested level.

We are keenly aware of budget constraints and competing interests for limited dollars. Unfortunately, despite the growing need, several domestic HIV/AIDS programs have experienced cuts in recent years including HIV prevention funding at the CDC, which



was flat funded in FY09. We are pleased that President Obama's budget blueprint "enhances HIV/AIDS Prevention and Treatment programs" and "increases resources to detect, prevent, and treat HIV/AIDS domestically, especially in underserved populations." We hope you will support the President's desire and increase funding for these important public health programs.

Below are the program requests and supporting explanation by The AIDS Institute:

**Centers for Disease Control and Prevention-HIV Prevention and Surveillance**

FY2009:	\$692 million
FY2010 Community Request:	\$1,570 million

As stated above, the CDC has increased the estimate of people infected each year by 40 percent. New infections are particularly occurring in certain populations, such as the poor, African-Americans, men who have sex with men, Latinos, substance users and the incarcerated. In order to address the specific needs of these populations and the increased number of people infected, CDC is going to need additional funding.

In response to these new incidence estimates, the House Committee on Oversight and Government Reform asked the CDC to develop a professional judgment budget outlining what funding is necessary for the CDC to improve HIV prevention efforts and reduce HIV transmission in the United States. The CDC's professional judgment budget called for an additional \$877 million in funding over the next five years.

Therefore, we are requesting that you increase CDC HIV prevention funding by \$877 million in FY10. With the additional funding the CDC estimates that by 2020 it could decrease the HIV transmission rate by 50 percent, reduce the number of people who do not know their status by 50 percent, and halve the disparities in the Black and Hispanic communities.

This additional funding would be targeted toward: 1) Increasing HIV testing and the number of people who are reached by effective prevention programs. Currently, 21 percent of HIV-positive people are unaware of their status, and they are 3.5 to 7 times more likely to infect others than people who are aware that they are positive; 2) developing new tools to fight HIV with scientifically-proven interventions; and 3) improving systems to monitor HIV and related risk behaviors, and to evaluate prevention programs.

Investing in prevention today will save money tomorrow. Every case of HIV that is prevented saves, on average, \$1 million of lifetime treatment costs for HIV. The CDC estimates that the cost of treating the estimated 56,300 new HIV infections in 2006 will translate into \$9.5 billion in annual future medical costs.

**Ryan White HIV/AIDS Programs**

FY2009:	\$2,238 million
FY2010 Community Request:	\$2,816 million

The centerpiece of the government's response to caring and treating low-income people with HIV/AIDS is the Ryan White HIV/AIDS Program. Ryan White currently serves over half a million low-income, uninsured, and underinsured people each year.

In FY09, the Program received an increase of \$72 million, or just 3.3 percent. This increase does not even cover the rate of inflation. The AIDS Institute urges you to provide substantial funding increases to all parts of the Ryan White Program. Consider the following:

- 1) Caseload levels are increasing. People are living longer due to lifesaving medications; there are over 56,000 new infections each year; and increased testing programs, according to the CDC, will identify 12,000 to 20,000 new people infected with HIV each year. With rising unemployment, people are losing their employer-sponsored health coverage. All of this will necessitate the need for more Ryan White services and medications.
- 2) The price of healthcare, including medications, is increasing and state and local budgets are experiencing cutbacks due to the economic downturn. A recent survey by the National Alliance of State and Territorial AIDS Directors found that fifty percent of ADAP programs have experienced or will experience state funding decreases in FY2009.
- 3) There are significant numbers of people in the U.S. who are not receiving life-saving AIDS medications. An IOM report concluded that 233,069 people in the U.S. who know their HIV status do not have continuous access to Highly Active Antiretroviral Therapy. A CDC study concluded 212,000, or 44% of eligible people living with HIV/AIDS, aged 15–49 in the US, are not receiving antiretroviral therapy.

Specifically, The AIDS Institute requests the following funding levels for each part of the Program:

**Part A** provides medical care and vital support services for persons living with HIV/AIDS in the metropolitan areas most affected by HIV/AIDS. We request an increase of \$103 million, for a total of \$766.1 million.

**Part B** base provides essential services including diagnostic, viral load testing and viral resistance monitoring and HIV care to all 50 states, DC, Puerto Rico, and the territories. We are requesting a \$105.4 million increase, for a total of \$514.2 million.

The **AIDS Drug Assistance Program (ADAP)** provides life-saving HIV drug treatment to over 140,000 people, the majority of whom are people of color (59%) and very poor (74% are at or below 200% of the federal poverty level). Due to a lack of funding, states have not been able to include all necessary drugs on their formularies, have limited eligibility and capped enrollment. In order to address the 8,472 new ADAP clients and drug cost increases, we are requesting an increase of \$268.6 million for a total of \$1,083.6 million.

**Part C** provides early medical intervention and other supportive services to over 248,000 people at over 380 directly funded clinics. We are requesting a \$66.4 million increase, for a total of \$268.3 million.

**Part D** provides care to over 84,000 women, children, youth, and families living with and affected by HIV/AIDS. This family-centered care promotes better health, prevents mother-to-child transmission, and brings hard-to-reach youth into care. We are requesting a \$57.7 million increase, for a total of \$134.6 million.

**Part F** includes the AIDS Education and Training Centers (AETCs) program and the Dental Reimbursement program. We are requesting a \$15.6 million increase for the AETC program, for a total of \$50 million, and a \$5.6 million increase for the Dental Reimbursement program, for a total of \$19 million.

The AIDS Institute supports increased funding for the **Minority AIDS Initiative (MAI)**. MAI funds services nationwide that address the disproportionate impact that HIV has on communities of color. We are requesting a \$200.5 million increase across the MAI's programs, for a total of \$610 million.

#### **National Institutes of Health-AIDS Research**

FY 2009:	\$3.3 billion (est.)
FY 2010 Community Request:	\$3.4 billion

Through the NIH, research is conducted to understand HIV and its complicated mutations, discover new drug treatments, develop a vaccine and other prevention programs such as microbicides, and ultimately develop a cure. Much of this work at the NIH is done in cooperation with private funding. The critically important work performed by the NIH not only benefits those in the U.S., but the entire world.

This research has already helped in the development of many highly effective new drug treatments, prolonging the lives of millions of people. As neither a cure nor a vaccine exists, and patients continue to build resistance to existing medications, additional research must continue. NIH also conducts the necessary behavioral research to learn how HIV can be prevented best in various affected communities. We ask the Committee to fund critical AIDS research at the community requested level of \$3.4 billion.

#### **Comprehensive Sex Education**

This past World AIDS Day, President Obama affirmed that, "My administration will ...work with Congress to enact an extensive program of prevention, including access to comprehensive age-appropriate sex education for all school age children." The federal government currently provides no federal funding solely dedicated to comprehensive sex education. We need to invest in programs that provide all of our young people with complete, accurate, and age-appropriate sex education that helps them reduce their risk of HIV/AIDS, other STDs, and unintended pregnancy. Programs that include information about both abstinence and condoms help keep young people safe by delaying sexual activity and increasing condom use when they do become sexually active. We request

that at least \$50 million be allocated to promote comprehensive sex education in our schools and communities nationwide.

**Administration for Children & Families: Community Based Abstinence Education**

Efforts to improve prevention methods and weed out non-effective programs should be a constant undertaking and be guided by science and fact based decision-making. It is for these reasons The AIDS Institute opposes abstinence-only-until-marriage programs. While we support abstinence-based prevention programs as part of a comprehensive prevention message, there is no scientific proof that abstinence-only programs are effective. On the contrary, they reject proven prevention tools, such as condoms, and fail to address the needs of gay men, who in most of the country cannot marry, and is the group most impacted by HIV/AIDS.

**Syringe Exchange Programs**

At least one quarter of all reported AIDS cases in our country are attributed to injection drug use through the sharing of needles and syringes. Federal scientific studies have repeatedly demonstrated that syringe exchange programs reduce the transmission of HIV and other infectious diseases without increasing or encouraging the use of illicit drugs, and may even help reduce drug use by creating a point of entry for addiction treatment. Today, there are nearly 200 such programs operating in 38 states, DC, and Puerto Rico. Despite their proven effectiveness, there is a ban on the use of federal funds for these programs. We urge you to lift the federal funding ban on syringe exchange programs in FY 2010.

**Viral Hepatitis**

Viral Hepatitis, whether A, B, or C, is an infectious disease that also deserves increased attention by the federal government. According to the CDC, there are an estimated 800,000 to 1.4 million Americans chronically infected with Hepatitis B, and 46,000 new infections each year. Although there is no cure, a vaccine is available and a few treatment options are available. An estimated 1.6 percent of Americans have been infected with Hepatitis C, of whom 3.2 million are chronically infected. Currently, there is no vaccine and very few treatment options. It is believed that one quarter of those infected with HIV are co-infected with Hepatitis C.

Given these numbers, we are disappointed the program is currently funded at a level that is substantially less than what it was funded in FY03 and falls far short of what is needed. These funds are needed to establish a program to lower the incidence of Hepatitis through education, outreach, and surveillance. We are requesting an increase of \$31.7 million for the program, for a total of \$50 million.

The AIDS Institute asks that you give great weight to our testimony as you deliberate over the FY2010 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Director of Federal Affairs, The AIDS Institute (202) 462-3042 or [cschmid@theaidsinstitute.org](mailto:cschmid@theaidsinstitute.org). Thank you very much.

**Alliance for Aging Research  
Testimony on FY 2010 National Institutes of Health Appropriations**

**Submitted to:  
House Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies**

**Submitted by:  
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**May 1, 2009**

Chairman Obey and members of the Subcommittee, for more than two decades the not-for-profit Alliance for Aging Research has advocated for research to improve the experience of aging for all Americans. Our efforts have included supporting federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other institutes and centers that work with the NIA on cross-cutting initiatives. To this end, the Alliance appreciates the opportunity to submit testimony highlighting the important role that the NIH plays in facilitating aging research activities and the ever more urgent need for increased appropriations to advance scientific discoveries to keep individuals healthier longer.

Many challenges will arise as Americans age in increasing numbers. There are approximately 36 million Americans aged 65 and older. That group is expected to double in size within the next 20 years, at which time at least 20 percent of the U.S. population will be older than 65. Of particular concern is the dramatic growth that is anticipated among those aged 85 and over. By 2050, 19.4 million Americans will be over the age of 85.

Late-in-life diseases such as type 2 diabetes, cancer, neurological diseases, heart disease, and osteoporosis are increasingly driving the need for healthcare services in this country. If rapid discoveries are not made now to reduce the prevalence of age-related diseases and conditions like these, the costs associated with caring for the oldest and sickest Americans will place an unmanageable burden on patients, their families, and our healthcare system. The Alliance strongly believes that with a relatively modest investment, further advances in the area of longevity science could yield tremendous health and economic benefits by shortening the period during which humans suffer from costly, debilitating diseases.

Within the NIH, the NIA leads research efforts to better understand the nature of aging and to maintain the health and independence of Americans as they grow older. The NIA supports a range of genetic, biological, clinical, social and economic research related to aging and the diseases of the elderly. Through the Division of Aging Biology, the NIA funds research focused

on understanding and exploiting the mechanisms underlying the aging process. Research supported by the Division of Aging Biology program is critically important in that much of it is centered around how changes in function considered to be “normal aging” become risk factors for many age-associated infirmities. Other noteworthy NIA-supported projects focus on increasing healthspan. These include studies to assess the beneficial effects of reducing caloric intake in animals, as well as those to test compounds that mimic this process in subjects with the potential to extend the years of disease-free life. Both approaches have produced promising results that may lead to insights into human applications. By capitalizing on these and other successful studies to identify genes that influence longevity, investigators hope to delay the onset of disease and disability associated with human aging in the future.

The NIA also participates in multi-institute collaborations on disease-specific research aimed at preventing, diagnosing, and more effectively treating age-related illnesses. Action to Control Cardiovascular Disease (ACCORD), led by the National, Heart, Lung, and Blood Institute in partnership with the NIA and three other NIH institutes, is a large clinical trial of adults with type 2 diabetes who are at high risk for cardiovascular disease. The trial involves the aggressive testing of interventions to reduce the burden of cardiovascular disease in high risk patients, many of whom are elderly. Major cardiovascular disease events result in death for 65 percent of diabetic patients and no effective preventative strategies currently exist for this vulnerable population. The Alzheimer’s Disease Neuroimaging Initiative (ADNI) is a major public-private partnership led by the NIA to evaluate imaging technologies, biological markers, and other tests to improve knowledge surrounding the progression of Alzheimer’s disease. ADNI has produced a wealth of data that is accessible to researchers worldwide. It is believed that ADNI findings could lead to shorter and less costly trials for Alzheimer’s therapies. As many as 5.3 million people have Alzheimer’s disease and it drains more than \$148 billion from the nation’s economy each year. Streamlined clinical trials could accelerate the development and approval of more effective AD treatments to the benefit of those who are yet to be diagnosed. The Diabetes Prevention Program, which was an NIH-supported clinical trial involving the NIA, continues to reveal information about diabetes onset, prevention and outcomes. It was initially intended to examine the effects of multiple interventions for adults at risk of type 2 diabetes. While it succeeded in identifying lifestyle changes that were particularly effective in the 60 and older population, it is the analysis of the long-term effects of these interventions on diabetes onset that could have the most impact on the 57 million adults who are at risk for developing the disease.

In general, the NIH is the primary funder of biomedical research in this country. Eighty percent of all the non-profit medical research in the U.S. is funded by the NIH. But the unfortunate reality is that shrinking budgets have impeded progress. In part the scarcity of resources has resulted in a decline of the overall success rate for NIH research grant applications. At its lowest point only one in four research proposals could be funded by the NIH. The effect of this has been reluctance on behalf of new investigators to submit truly ground-breaking research proposals for consideration. While we recognize that there is enormous competition for congressional appropriations each year, a lack of sustained funding for the NIH will have a devastating impact on the rate of basic discovery and the development of interventions that could have the significant public health benefits for our aging population.

Until recent actions taken by Congress and the President to provide a short-term resource infusion through passage of the American Reinvestment and Recovery Act, funding for the NIH had been on a downward trajectory. In the six years through 2008, a series of nominal increases and cuts has amounted to flat funding for the NIH, and as a result it has lost as much as 17% of its purchasing power. Aging in particular is a field of research that had been hampered by this stagnant funding. To operate in this environment the NIA and other institutes involved in aging-related research have not been able to fund increasing numbers of high-quality research grants each year.

The Alliance for Aging Research applauds Congress and the Obama Administration's renewed focus on the importance of medical research in improving the overall health of the country. In order to demonstrate a strong commitment to bolstering science, we would recommend an increase in funding for the NIH of at least 7 percent in FY 2010. This increase would begin to restore the NIH's ability to pursue new basic, translational, and clinical research opportunities. A \$32.4 billion budget for the NIH in FY2010 would allow the NIA specifically to increase support of new and existing investigator initiated research projects and better facilitate the acceleration of discoveries for a wide range debilitating age-related diseases and conditions among our growing population of older Americans.

Mr. Chairman, the Alliance for Aging Research thanks you for the opportunity to outline the challenges posed by the aging population that lie ahead as you consider the FY 2010 appropriations for the NIH and we would be happy to furnish additional information upon request.

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**Alzheimer's Association**  
 Testimony Submitted to  
 Labor-HHS-Education Appropriations Subcommittee  
 regarding the National Institutes of Health, CDC and Administration on Aging  
 by  
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Mr. Chairman and members of the Subcommittee-

As President and CEO of the Alzheimer's Association, I want to take this opportunity to thank you for the leadership role this Subcommittee has played over the years in the fight to conquer Alzheimer's disease.

Indeed, it was this Subcommittee that first drew attention to Alzheimer's disease in its fiscal year 1982 appropriations report. At the time, an estimated 2.5 million people were thought to be suffering with Alzheimer's disease, their families quietly bearing most of the financial, physical and emotional burden of care giving. Even if they were personally affected, relatively few Americans had even heard of Alzheimer's disease because so many went undiagnosed or were inaccurately diagnosed; far fewer were aware of the crisis just beginning to unfold. All this is still too true today.

Alzheimer's disease now is now estimated to afflict more than 5 million Americans. It is in a virtual tie as the nation's sixth leading cause of death, while significantly underreported and growing. It is already the third most expensive disease, draining billions of dollars from our economy every year. But the story does not end with those grim statistics because this problem is not going to age itself away. On the contrary, as Baby Boomers shoulder their way into the age of highest risk, we will see 10 million members of this generation fall victim to Alzheimer's disease.

At times called the quiet epidemic, the great unlearning or the long dying, year by year Alzheimer's disease strips away memory, personality and independence, leaving its victims unable to handle the most basic functions of daily living. For those who do not succumb to pneumonia or other complications of Alzheimer's, there is the final act of forgetting—when the brain forgets to breathe.

But make no mistake: The effects of Alzheimer's extend well beyond the human suffering and the physical and emotional strain it puts on families. Indeed, despite all that is challenging America today, Alzheimer's disease represents a grave threat to our Nation's social and economic well-being.

This year, Medicare and Medicaid will spend more than \$100 billion to finance care for those struggling with Alzheimer's disease. Over the next 40 years, those two programs alone will spend almost \$20 trillion on the care of Alzheimer patients.



Unless we find a way to prevent or slow its progression, by the year 2050 the annual cost of this disease to Medicare and Medicaid programs alone will be equal to one-tenth of our entire current domestic economy.

Alzheimer's disease is so expensive because, in addition to its direct costs, it greatly increases the use and costs of Medicare to treat other serious medical conditions. Ninety-five percent of Medicare beneficiaries with Alzheimer's disease have at least one co-morbid condition. Tasks such as medication management become extremely difficult and time-consuming. As a result, the health and long-term care costs of treating these individuals is more than three times that of a Medicare beneficiary without Alzheimer's disease.

#### **Bold Action is Needed Now**

Over the years this body has exercised its prerogative to channel funds to the nation's most pressing public health problems. Added funds provided by this Subcommittee led to cancer patients living longer, with many beating the disease. Thanks to those investments, survival rates have steadily improved for breast, prostate, colorectal and some other types of cancer, so that today, the 5 year relative survival rate is 66% across all cancers. According to the most recent estimates, 10.8 million Americans with a history of cancer are alive today. As a result of this Subcommittee's strong and sustained investment in cardiovascular disease research, death rates from heart disease and stroke fell by 40 percent and 51 percent, respectively, since 1975. And when challenged by the HIV/AIDS epidemic, this Subcommittee responded quickly and decisively—providing a research investment that yielded vastly improved treatments and prevention strategies and a two-thirds reduction in annual deaths.

Mr. Chairman, unlike cancer, cardiovascular disease and so many other chronic conditions that have dramatically improved with significant investments in research, there are no Alzheimer's disease survivors. None. We cannot prevent, halt or reverse it. Every day some of the 5 million who have it die of this fatal disease, only to be replaced by even more who will progressively decline and die, as more replace them. Indeed, the only way to avert this rapidly developing social and economic catastrophe is if this Subcommittee, once again, leads the way.

Past investments in Alzheimer's research have helped bring us to a point no one would have dreamed possible when this Subcommittee first called attention to this disease. Scientists now have a much clearer, but still incomplete picture of the basic mechanisms of Alzheimer's; epidemiological research is shedding light on new targets for intervention that now must be tested in large-scale clinical trials. And work is underway to help identify potential uses of imaging and other surrogate markers to follow the progression of cognitive decline, and to assess the effectiveness of drug interventions. But we still have so much to accomplish.

Much of what we have learned came about because Congress invested in Alzheimer research throughout the 1980s and 1990s. But even those investments were not

commensurate with the impact of the disease. The evidence from cancer and cardiovascular disease illustrates the returns that can be derived from additional investments in Alzheimer's research now. As the mortality rates for cancer and heart disease decline, Alzheimer's is still rising at a steady and rapid pace.

In fact, during the past six years we have seen a dramatic slowdown in overall research investments, signaling a slowdown in advances to come, but the effects on Alzheimer research are potentially greater as the funding stalled at such a comparatively low level. Today, the National Institutes of Health devotes only \$412 million a year for research on Alzheimer's disease—far short of the \$1 billion that leading scientific minds estimate as the minimum required investment to uncover ways to prevent, slow and more effectively treat this disease. That \$412 million is also considerably less than what is spent for research on other major threats to society, such as cancer, cardiovascular disease and AIDS. All of these problems merit significant investments, but Alzheimer's research is underfunded when measured against the suffering inflicted by the disease or by the potential cost savings in care that could be gained by investing in research today—before it's too late.

What can the Subcommittee do to help stop this serious threat to America's future?

**First and foremost, the Alzheimer's Association recommends that you appropriate an additional \$250million this year and next to raise the total NIH investment in Alzheimer's research up to \$1 billion.** These added funds will be put to use in three crucial areas:

- **Clinical trials** – The funding of clinical trials and epidemiological studies, particularly through the Alzheimer's Disease Cooperative Study (ADCS) national research consortium funded by the NIH, are identifying new targets for interventions, including compounds that are already widely available such as over-the-counter medications. Time is not on our side. If we hope to forestall this looming crisis, large-scale clinical trials must be undertaken soon and must be launched simultaneously, not sequentially.
- **Early markers of disease** - Earlier diagnosis is critical if we hope to stop the disease before it ravages brain cells beyond repair. Additional resources are sorely needed to fully fund the next phase of a neuro-imaging initiative currently being supported at the National Institute on Aging.
- **Basic science research** - Science must find new answers and ask better questions. While significant progress has been made, scientists are still searching for definitive answers to questions about the basic mechanisms of Alzheimer's disease. Congress must maintain the pipeline of basic scientific discovery to develop additional targets for treatment. At current funding levels, work on promising avenues of research is either delayed or never started. Young investigators—and their fresh new ideas—are discouraged from entering this field of study.

While research holds the answers, there are other steps we recommend you take to help forestall or lessen the impact of Alzheimer's.

#### **Expand the Healthy Brain Initiative to \$5 million**

Four years ago, this Subcommittee launched the first single-focused effort on brain health promotion at the Centers for Disease Control and Prevention. As a result of the investment that has been made in the Healthy Brain Initiative, the CDC, in partnership with the Alzheimer's Association, has developed a public health roadmap for maintaining cognitive health, implemented community education programs targeting African-American baby boomers, and developed modules for enhancing the surveillance system for cognitive decline.

The impetus for this program was the mounting scientific evidence suggesting that brain health may be maintained by preventing or controlling cardiovascular risk factors, such as high blood pressure, high cholesterol and diabetes, and by engaging in regular physical activity. In light of the dramatic aging of the population, scientific advancements in risk behaviors, and the growing awareness of the significant health, social and economic burdens associated with cognitive decline, the federal investment in a public health response must be expanded. We recommend that this program be increased to \$5 million to focus on the following activities:

- *Healthy Brain Engagement Initiative* – The promising approaches that have been identified through the community education programs need to be expanded to additional locations and new target audiences to impact attitudes and behaviors related to cognitive health. Particularly, we must focus on other high-risk and underserved populations, specifically the Hispanic/Latino population.
- *Tracking Cognitive Impairment as America Ages* – In order to accelerate the availability of data to clarify the burden of Alzheimer's, an enhanced surveillance system for cognitive health is required. This can be achieved through implementation of appropriate Behavioral Risk Factor Surveillance System (BRFSS) modules in as many states as possible. The development and testing of BRFSS modules is currently underway and will be available for use in 2010.
- *Tools for Care Coordination in the Face of Cognitive Impairment* – Cognitive health challenges – from mild cognitive decline to dementia – can have profound implications on an individual's ability to self-manage other coexisting conditions. In order to effectively address this challenge, interventions that target the coordination of care for those with cognitive impairment and coexisting chronic diseases will be adapted or developed.
- *Early Detection* – Early recognition of Alzheimer's, an accurate diagnosis, and early intervention, including medication, can significantly improve the quality of life and mental function of people with the disease. Communications strategies that provide information on the signs and symptoms of the disease and options for

maintaining brain health will be developed and disseminated, targeting consumers and providers.

**Continue Alzheimer's Disease Demonstration Grants and the Alzheimer's Contact Center**

The Administration on Aging (AoA) operates two Alzheimer-related programs that warrant continuation. The first is a program of matching grants to States for the development of innovative, community-based services for Alzheimer patients and caregivers, especially hard-to-reach and underserved populations. For this program, we recommend an appropriation of \$11.6 million.

In 2003, this Subcommittee launched the Alzheimer's Contact Center, a nationwide call-in program that provides families in crisis with around-the-clock support and assistance. Services include access to professional clinicians who provide decision-making support, crisis assistance and referrals. In 2008, the center fielded more than 106,000 calls from families. The Alzheimer's Association recommends you appropriate \$1 million to continue this valuable service.

Each of the recommendations I have outlined fall within the purview of this Subcommittee. But I would also like to call your attention to a report issued recently, called *A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group*.

This landmark report was the culmination of nearly two years of work by an independent taskforce of prominent national leaders. It was co-chaired by former Speaker of the House Newt Gingrich and former U.S. Senator Bob Kerrey, and included other distinguished individuals such as former Supreme Court Justice Sandra Day O'Connor and Drs. Harold Varmus, David Satcher and Mark McClellan. The Alzheimer's Study Group also drew on the knowledge and expertise of more than 100 experts in various facets of this disease.

Mr. Chairman, in a word, the Alzheimer's Study Group concluded that to achieve a world without Alzheimer's disease we do not need to re-invent the wheel; but we have to make it work more efficiently.

This report contains many important recommendations, including developing the capability to prevent Alzheimer's disease in 90 percent of individuals by 2020. But one that warrants special attention within the context of this Subcommittee's deliberations is the creation of an outcomes-oriented, objective-driven Alzheimer's Solutions Project Office within the federal government. With support from the president and Congress, this effort would oversee a decade-long mission to undertake a coordinated and sustained attack on Alzheimer's disease.

Mr. Chairman, thank you for your time and attention. Should you have any questions or require additional information, please feel free to call on me.



**Ted D. Epperly, MD, FAAPF, President**  
**American Academy of Family Physicians**  
 Public Witness Testimony for the House  
 Appropriations Labor/HHS/Education  
 Subcommittee – May 1, 2009  
 capitol@aafp.org - 202-232-9033

On behalf of the American Academy of Family Physicians (AAFP), I want to thank the House Appropriations Committee for demonstrating its commitment to a strong primary care workforce by seeking to double the appropriation for training under Title VII Section 747 of the Public Health Services Act in the American Recovery and Reinvestment Act of 2009 (ARRA). As one of the largest national medical organizations, representing family physicians, residents, and medical students, the AAFP is pleased to recommend that the House Appropriations Subcommittee on Labor, Health and Human Services, and Education continue that commitment to Title VII Section 747 in fiscal year 2010 and increase funding for other key HHS programs to allow health care reform to succeed and support better health care all.

#### **HEALTH RESOURCES AND SERVICES ADMINISTRATION**

The Health Resources and Services Administration (HRSA) is charged with improving access to health care services for people who are uninsured, isolated or medically vulnerable. One of the most critical aspects of this mission is ensuring a health care workforce which is sufficient to meet the needs of patients and communities.

#### **HRSA—HEALTH PROFESSIONS**

For 40 years, the training programs authorized by Title VII of the *Public Health Services Act* evolved to meet our nation's health care workforce needs. While it is increasingly clear that our nation has a worsening shortage of primary care physicians, many "studies have found a strong, sometimes dose-dependent associations between Title VII funding and increased production of primary care graduates, and physicians who eventually practice in rural areas and federally designated physician shortage areas."<sup>1</sup>

The sixth report of the Health Resources and Services Administration (HRSA) Advisory Committee on Training in Primary Care Medicine and Dentistry recommended an annual minimum level of \$215 million for the Title VII Section 747 grant program. The Committee reasoned that:

Title VII funds are essential to support major primary care training programs that train the providers who work with vulnerable populations. It is critical that funds not only be restored to 2005 levels, but that funding be increased, as the need for healthcare of

<sup>1</sup> Robert Graham Center. *Specialty and Geographic Distribution of Physician Workforce: What Influences Medical Student & Resident Choices?* 2009 Washington, DC.

the public, including those high-risk groups identified in this report, increases. It is critical that funds offset the acknowledged rate of inflation. This additional funding is also necessary to prepare current and future primary care providers for their critical role in responding to healthcare challenges including demographic changes in the population, increased prevalence of chronic conditions, decreased access to care, and a need for effective first-response strategies in instances of acts of terrorism or natural disasters.

Health care reform demands that we must modernize workforce and education policies to ensure an adequate number of primary care physicians trained to serve in the new health care delivery model. The patient centered medical home will give patients access to preventive care and coordination of the care needed to manage chronic diseases as well as appropriate care for acute illness. The medical home practice model provides improved efficiency and better health because it serves as a principal source of access and care. As a result, duplication of tests and procedures and unnecessary emergency department visits and hospitalizations can be avoided

Section 747 of Title VII, the Primary Care Medicine and Dentistry Cluster, is aimed at increasing the number of primary care physicians (family physicians, general internists and pediatricians). Section 747 offers competitive grants for family medicine training programs in medical schools and in residency programs. Section 747 is vital to stimulate medical education, residency programs, as well as academic and faculty development in primary care to prepare physicians to support the patient centered medical home.

The value of Title VII grants extends far beyond the medical schools that receive them. The United States lags behind other countries in its focus on primary care. However, the evidence shows that countries with primary care-based health systems have population health outcomes that are better than those of the U.S. at lower costs.<sup>2</sup> Health Professions Grants are one important tool to help refocus the nation's health system on primary care.

Although HRSA has not released the spending plan for the ARRA health professions training funds for FY 2009-2010, the omnibus appropriation increased Section 747 by less than one percent over the final FY 2008 amount to \$48,425,000 for FY 2009. It remains well below the \$92 million provided for Primary Care Medicine and Dentistry Training in FY 2003. The nation needs significant additional support from Section 747 because it is the only national federally-funded program that provides resources for important innovations necessary to increase the number of physicians who will lead the primary care teams providing care in patient centered medical homes.

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<sup>2</sup> Starfield B, et al. The effects of specialist supply on populations' health: assessing the evidence. *Health Affairs*. 15 March 2005.

**AAFP recommends a substantial increase in the fiscal year 2010 appropriation bill for the Health Professions Training Programs authorized under Title VII of the Public Health Services Act. We respectfully request that the Committee provide \$215 million for the Section 747, the Primary Care Medicine and Dentistry Cluster, which will signal the commitment of Congress to reform health care delivery in this nation.**

#### **HRSA—NATIONAL HEALTH SERVICE CORPS**

The National Health Service Corps (NHSC) offers scholarship and loan repayment awards to primary care physicians, nurse practitioners, dentists, mental and behavioral health professionals, physician assistants, certified nurse-midwives, and dental hygienists serving in underserved communities. Research has shown that debt plays a complex yet important role in shaping career choices for medical students. The NHSC offers financial incentives for the recruitment and retention of family physicians to practice in underserved communities without adequate access to primary care. The AAFP supports the work of the NHSC toward the goal of full funding for the training of the health workforce and zero disparities in health care.

**AAFP respectfully requests that the Committee fully fund these important scholarship and loan repayment programs by providing the authorized amount of \$235 million for NHSC in fiscal year 2010.**

#### **HRSA—RURAL HEALTH**

Americans in rural areas face more barriers to care than those in urban and suburban areas. Rural residents also struggle with the higher rates of illness associated with lower socioeconomic status.

Family physicians provide the majority of care for America's underserved and rural populations.<sup>3</sup> Despite efforts to meet scarcities in rural areas, the shortage of primary care physicians continues. Studies, whether they be based on the demand to hire physicians by hospitals and physician groups or based on the number of individuals per physician in a rural area, all indicate a need for additional physicians in rural areas.

HRSA's Office of Rural Health administers a number of programs to improve health care services to the quarter of our population residing in rural communities. Rural Health Policy Development and Outreach Grants fund innovative programs to provide health care in rural areas. State rural health offices, funded through the National Health Services Corps budget, help states implement these programs so that rural residents benefit as much as urban patients.

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<sup>3</sup> Hing E, Burt CW. Characteristics of office-based physicians and their practices: United States, 2003–04. Series 13, No. 164. Hyattsville, MD: National Center for Health Statistics. 2007.

**AAFP encourages the Subcommittee to provide adequate funding in the fiscal year 2010 appropriation bill for the important programs administered by HRSA's Office of Rural Health to address the many unique health service needs of rural communities.**

#### **AGENCY FOR HEALTHCARE RESEARCH AND QUALITY**

The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of health care for all Americans—closely mirrors AAFP's own mission. AHRQ is a small agency with a huge responsibility for research to support clinical decision-making, reduce costs, advance patient safety, decrease medical errors and improve health care quality and access. Family physicians recognize that AHRQ has a critical role to play in promoting health care safety, quality and efficiency initiatives.

#### **AHRQ—COMPARATIVE EFFECTIVENESS RESEARCH**

One of the hallmarks of the patient centered medical home is evidence-based medicine. Comparative effectiveness research, which compares the impact of different options for treating a given medical condition, is vital to quality care. Studies comparing various treatments (e.g., competing drugs) or differing approaches (e.g., surgery and drug therapy) can inform clinical decisions by analyzing not only costs but the relative medical benefits and risks for particular patient populations.

AAFP commends the Congress for including \$1.1 billion in ARRA for comparative effectiveness research which holds out the promise of reducing health care costs while improving medical outcomes.

**AAFP respectfully suggests that the Committee provide at least \$405 million for AHRQ in the fiscal year 2010 appropriations bill, an increase of \$32 million above the fiscal year 2009 level.**





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Federal Affairs Department

**AMERICAN ACADEMY OF OPHTHALMOLOGY  
WRITTEN TESTIMONY IN SUPPORT OF INCREASED  
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)  
AND THE NATIONAL EYE INSTITUTE (NEI)  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES  
APPROPRIATIONS SUBCOMMITTEE  
April 29, 2009**

**EXECUTIVE SUMMARY:**

**The American Academy of Ophthalmology requests a Fiscal Year (FY) 2010 NIH funding increase of at least seven percent, to a level of \$32.4 billion, which represents a modest three percent increase plus the biomedical inflation rate, estimated at 3.8 percent in FY2009. This increase is necessary to keep pace with inflation and rebuild the base, since NIH has lost 14% of its purchasing power during the past six funding cycles.** The Academy commends the Congressional leadership's actions in FY2008 and 2009 to increase NIH funding, including the \$150 million in the FY2008 supplemental dedicated to investigator-initiated grants, the \$10.4 billion two-year stimulus NIH funding within the American Recovery and Reinvestment Act (ARRA), and the final FY2009 appropriations inflationary increase of 3.2 percent. However, NIH needs sustained and predictable funding to rebuild its base and support multi-year investigator-initiated research, which is the cornerstone of the biomedical enterprise. Annual increases of at least seven percent put NIH on a pathway to budget-doubling within the next ten years. Secure and consistent funding for biomedical research is integral to the nation's economic and global competitiveness. NIH is a world-leading institution that must be adequately funded so that its research can reduce healthcare costs, increase productivity, and save and improve the quality of lives.

**The Academy requests that Congress make vision health a top priority by increasing NEI funding by at least 7 percent, to a level of \$736 million, in this year that NEI celebrates its 40<sup>th</sup> anniversary. Over the past six funding cycles, NEI lost 18 percent of its purchasing power.** Despite funding challenges, NEI has maintained its impressive record of breakthroughs in basic and clinical research that have resulted in treatments and therapies to save and restore vision and prevent eye disease. NEI will be challenged further, as 2010 begins the decade in which more than half of the 78 million Baby Boomers will turn 65 and be at greatest risk for aging eye disease. Adequately funding the NEI is a cost-effective investment in our nation's health, as it can delay, save, and prevent expenditures, especially to the Medicare and Medicaid programs.

**FY2010 FUNDING AT \$736 MILLION ENABLES NEI TO EXPAND ITS IMPRESSIVE RECORD OF BASIC AND CLINICAL COLLABORATIVE RESEARCH THAT HAS RESULTED IN TREATMENTS AND THERAPIES TO SAVE AND RESTORE VISION AND PREVENT EYE DISEASE**

Immediately after President Obama signed the ARRA, Acting NIH Director Raynard Kington, M.D., Ph.D., identified the major health challenges that NIH faces, especially when describing the potential emphasis of the newly created "Challenge Grants": the shift from acute to chronic diseases, and the attendant co-morbid conditions; an aging population; health disparities; and prevention. Since its creation 40 years ago, the NEI has been directly addressing these issues as they apply to vision and has been a leader in what former NIH Director Elias Zerhouni, M.D., has described as the 21<sup>st</sup> century paradigm for healthcare research and clinical practice, or "P4 Medicine"—that which is predictive, preemptive, personalized, and participatory.

NEI continues to be a leader in basic research—especially that which elucidates the genetic basis of ocular disease—and in translational research, as those gene discoveries can lead to development of diagnostics and treatments. NEI Director Paul Sieving, M.D., Ph.D., has reported that one-quarter of all genes identified to date through NEI's collaboration with the National Human Genome Research Institute (NHGRI) are associated with eye disease/visual impairment. Recent examples include:

- In 2005, NEI reported that gene variants of Complement Factor H (CFH), the protein product of which is engaged in the control of the body's immune response, are associated with increased risk of developing age-related macular degeneration (AMD), the leading cause of vision loss. NEI-funded researchers are now working on potential therapies, including the manufacture and use of a protective version of the CFH protein in an augmentation strategy similar to that of treating diabetes with insulin. This therapy is under development and expected to enter Phase I clinical safety trials in summer 2009. These same researchers are also conducting research in individuals with liver transplants, since most CFH is made in the liver, to see what happens when an individual receives a different form of CHF. The researchers hope that these studies reinforce the concept of providing AMD patients with doses of the protective protein or, in the future, with gene therapy approaches that would allow the liver to produce the protein on its own. Researchers have also reported relationships between CFH and obesity, coronary artery disease, myocardial infarction, and stroke, among other conditions—the findings of which facilitate new opportunities for trans-NIH research.
- In addition to gene-based approaches to develop AMD treatments, NEI's collaborative research into factors that inhibit new blood vessel growth has in part fostered the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing and restoring vision, and NEI's Diabetic Retinopathy Clinical Research (DRCR) Network is further evaluating these drugs for treatment of macular edema associated with diabetic retinopathy (DR). In March 2008, NEI-funded researchers announced that damage from both AMD and DR was prevented and even reversed when the protein Robo4

was activated in mouse models that simulate the two diseases. Robo4 treated and prevented the diseases by inhibiting abnormal blood vessel growth and by stabilizing blood vessels to prevent leakage. Since this research into the "Robo4 Pathway" used animal models associated with these diseases that are already used in drug development, the time required to test this approach in humans could be shortened, expediting approvals for new therapies

- In late April 2008, researchers funded by the NEI and private funding organization Foundation Fighting Blindness reported on their use of gene therapy to restore vision in young adults who were virtually blind from a severe form of the neurodegenerative disease Retinitis Pigmentosa, known as Leber Congenital Amaurosis (LCA). Seven years earlier, the researchers shared on Capitol Hill results of a preclinical study of the same gene therapy, which at the time was successfully giving vision to dogs born blind with LCA. The subsequent human gene therapy trial validated the process of putting genes in the body to restore vision. Although the primary goal of the Phase I study was to ensure patient safety, the researchers reported through both objective and subjective testing that the patients were able to read several additional lines on an eye chart, had better peripheral vision, and better eyesight in dimly lit settings. In further research, the investigators will treat LCA patients as young as eight years old, since they believe the most dramatic results will be seen in young children
- In late 2008, NEI initiated its new NEI Glaucoma Human genetics collaboration, known as NEIGHBOR, through which seven U.S. research teams will lead genetic studies of the disease. Glaucoma is called the "stealth robber of vision" as it often has no symptoms until vision is lost, and anywhere from 50-75 percent of individuals with it are undiagnosed. It is also the leading cause of preventable vision loss in African American and Hispanic populations. Previously, in a March 13-14, 2008, joint *Glaucoma Endpoints* meeting with the FDA, NEI-funded researchers acknowledged that glaucoma is a complex, neurodegenerative disease in which detectable changes within the eye may not progress linearly or in concert with functional changes, that is, vision loss. All of these factors emphasize the vital nature of determining the genetic basis of this disease.

#### **FY2010 FUNDING AT \$736 MILLION ENABLES NEI TO FULLY FUND NEW INITIATIVES THAT MORE FULLY CHARACTERIZE EYE DISEASE**

NEI has been a leader in collaborative research, the use of networks to study diagnostics and treatments and their use in clinical settings, and in ocular epidemiology to characterize the nature and frequency of eye disease in diverse populations to better manage public health. In FY2008, NEI reported on/launched the initial phase of three important new programs to characterize eye disease that will require adequate future funding.

- In early 2009, the NEI and the National Aeronautics and Space Administration (NASA) reported on the use of a compact fiber optic probe developed for the space program that has proven valuable as the first non-invasive early detection device for cataracts, the leading cause of vision loss worldwide. Using a laser light technique called dynamic light scattering (DLS), which was developed to analyze the growth of protein crystals in a zero-gravity environment, the probe measures the amount of light scattering by an anti-cataract protein called alpha-crystallin. This protein binds to other

proteins when they become damaged, thus preventing them from bunching together to form a cataract. Since humans are born with a fixed amount of alpha-crystallin, if it is depleted due to radiation exposure, smoking, diabetes, or other causes, a cataract can result. The probe senses protein damage due to oxidative stress, a key process involved in many medical conditions including age-related cataract and diabetes, as well as Alzheimer's and Parkinson's disease

- In late 2008, NEI launched a new research network, the Neuro-Ophthalmology Research Disease Investigator Consortium, or NORDIC. There is a broad spectrum of neuro-ophthalmic disorders that collectively affect millions of people. However, since many of the visual disorders associated with other systemic and neurologic conditions fit the definition as "rare" diseases, they have not been adequately studied. NORDIC will initially lead multi-site observational and treatment trials, involving nearly 200 community and academic practitioners, to address the risks, diagnosis, and treatment of two such "rare" diseases: idiopathic intracranial hypertension (visual dysfunction due to increased intracranial pressure) and thyroid eye disease (also called Graves' disease, in which muscles of the eye enlarge and cause bulging of the eyes, retraction of the lids, double vision, decreased vision, and irritation). The network's structure enables it to study additional conditions. The NEI and NORDIC's Principal Investigator have already begun coordinating with the Department of Defense's (DOD) newly established Vision Center of Excellence (VCE) about the applicability of NORDIC research to combat-related eye injuries, especially those associated with Traumatic Brain Injury (TBI), which is being experienced in record numbers in Iraq and Afghanistan.
- There is currently almost no information on the prevalence, risk factors, and genetic determinants in Asian Americans— one of the fastest growing racial groups in the US. Studies from East Asia have suggested that Asians have a spectrum of eye diseases different from that of White Americans, African Americans, and Hispanics. In late 2008, NEI launched the Chinese American Eye Study to characterize the extent of eye disease in Chinese Americans, the largest Asian sub-group in the US. Participants 50 years and older will be evaluated for blindness, visual impairment, and eye disease. The observations will add to the expanding body of knowledge about aging eye disease. Past NEI-funded studies have yielded dramatic findings— the Ocular Hypertension Treatment Study (OHTS) reported that African Americans have a four-fold greater risk of developing glaucoma than White Americans, and the Los Angeles Latino Eye Study (LALES) found increased incidence of glaucoma and diabetic retinopathy in individuals of Mexican descent. All of these studies assist in developing public health policy, especially in relation to education, prevention, rehabilitation, and eye care services.

**VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT INCREASES HEALTHCARE COSTS, REDUCES PRODUCTIVITY, AND DIMINISHES QUALITY OF LIFE**

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year

2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is \$68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As recently as March 2008, the NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life.

In 2009, the NEI will celebrate its 40<sup>th</sup> anniversary as the NIH Institute that leads the nation's commitment to save and restore vision. During the next decade, more than half of the 78 million Baby Boomers will celebrate their 65th birthday and be at greatest risk for developing aging eye disease. As a result, sustained, adequate federal funding for the NEI is an especially vital investment in the health, and vision health, of our nation as the treatments and therapies emerging from research can preserve and restore vision. Adequately funding the NEI can also delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

**The American Academy of Ophthalmology urges FY2010 NIH and NEI funding at \$32.4 billion and \$736 million, respectively, reflecting an at-least seven percent increase over FY2009.**

#### **ABOUT THE AMERICAN ACADEMY OF OPHTHALMOLOGY**

The American Academy of Ophthalmology is a 501c (6) educational membership association. The Academy is the largest national membership association of Eye M.D.s with more than 27,000 members, over 17,000 of which are in active practice in the United States. Eye M.D.s are ophthalmologists, medical and osteopathic doctors who provide comprehensive eye care, including medical, surgical and optical care. More than 90 percent of practicing U.S. Eye M.D.s are Academy members.

**Fiscal Year 2010 Appropriations**

Submitted by: Kimberly Beer, LGPC, Assistant Director, Federal Affairs,  
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TESTIMONY OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS  
 SUBMITTED TO THE  
 SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION  
 AND RELATED AGENCIES  
 COMMITTEE ON APPROPRIATIONS  
 UNITED STATES HOUSE OF REPRESENTATIVES  
 REGARDING FISCAL YEAR 2010 APPROPRIATIONS

April 30, 2009

On behalf of the more than 75,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on FY 2010 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the Academy supports the HPNEC recommendation to provide at least \$300 million for Title VII programs in FY 2010, including a minimum of \$7 million to support PA educational programs. This would fund the programs at the 2005 funding level, not accounting for inflation.

AAPA recommends that Congress provide additional support to grow the PA primary care workforce through health care reform initiatives. A reformed health care system will require a much-expanded primary health care workforce, both in the private and public health care markets. For example, the National Association of Community Health Centers' March 2009 report, *Primary Care Access: An Essential Building Block of Health Reform*, predicts that in order to reach 30 million patients by 2015, health centers will need at least an additional 15,585 primary care providers, just over one third of whom are non-physician primary care professionals.

The Academy believes that the recommended restoration in funding for Title VII health professions programs is well justified.

***A review of PA graduates from 1990 – 2006 demonstrates that PAs who have graduated from PA educational programs supported by Title VII are 59% more likely to be from underrepresented minority populations and 46% more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII.***

***A study by the UCSF Center for California Health Workforce Studies found a strong association between physician assistants exposed to Title VII during their PA***

*educational preparation and those who ever reported working in a federally qualified health center or other community health center.*

Title VII safety net programs are essential to the development and training of primary health care professionals and, in turn, provide increased access to care by promoting health care delivery in medically underserved communities. Title VII funding is especially important for PA programs as it is the only federal funding available on a competitive application basis to these programs.

The AAPA is very appreciative of the recent funding increases, for the Title VII Health Professions Programs, in the FY 2009 Omnibus Appropriations bill (P.L. 111-8), which appropriated \$221.7 million, a 14.3% increase, over FY'08 and the American Recovery and Reinvestment Act (P.L. 111-5), which invested \$200 million in expanding Title VII Health Professions Programs. However, the AAPA believes that these recent investments only begin to rectify the chronic underfunding of these programs and address existing and looming shortages of health professionals, especially physician assistants. According to HRSA, an additional 30,000 health practitioners are needed to alleviate existing health professional shortages.

We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to restore funding to these important programs in FY 2010 to the FY 2005 funding level.

#### **Overview of Physician Assistant Education**

Physician assistant programs train students to practice medicine with physician supervision. PA programs are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about four years of prior health care experience. The first phase of the program consists of intensive classroom and laboratory study. More than 400 hours in classroom and laboratory instruction are devoted to the basic sciences, with over 75 hours in pharmacology, approximately 175 hours in behavioral sciences, and almost 580 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours, or 50-55 weeks, to clinical education, divided between primary care medicine – family medicine, internal medicine, pediatrics, and obstetrics and gynecology – and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

After graduation from an accredited PA program, physician assistants must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education hours every two years, and they must take a recertification exam every six years.

#### **Physician Assistant Practice**

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are allowed by law and are within the physician's scope of practice and the PA's training and experience. All states, the District of Columbia, and Guam authorize physicians to delegate prescriptive privileges to the PAs they supervise. Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 41 percent of PAs work in urban and inner city areas. Approximately 40 percent of PAs are in primary care. Roughly 80 percent of PAs practice in outpatient settings.

AAPA estimates that in 2008, over 257 million patient visits were made to PAs and approximately 332 million medications were written by PAs.

#### **Critical Role of Title VII Public Health Service Act Programs**

Title VII programs promote access to health care in rural and urban underserved communities by supporting educational programs that train health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, increase access to care in underserved communities, and increase minority representation in the health care workforce.

Title VII programs are the only federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities – the purpose of Title VII.

Furthermore, Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step towards reducing persistent health disparities among certain racial and ethnic U.S. populations. Studies have found that health professionals from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care.

It is also important to note that a December 2008 Institute of Medicine report characterized HRSA's health professions programs as "an undervalued asset."

#### **Title VII Support of PA Educational Programs**



Targeted federal support for PA educational programs is authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, P.L. 105-392, which streamlined and consolidated the federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

P.L. 105-392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to an affordable education and encourage PAs, upon graduation, to practice in underserved communities. **These goals are accomplished by funding PA educational programs that have a demonstrated track record of: 1) placing PA students in health professional shortage areas; 2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and 3) recruiting and retaining students who are indigenous to communities with unmet health care needs.**

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of Web based and distant learning technology and methodologies so students can remain at clinical practice sites. In New York, a PA program with a 90% ethnic minority student population uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the needs of medically underserved areas or disadvantaged students. The need is very real, and Title VII is critical in meeting that need.

#### **Need for Increased Title VII Support for PA Educational Programs**

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without Title VII funding to expose students to underserved sites during their training, PA students are

far more likely to practice in the communities where they were raised or attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 2006 article in the *Journal of the American Medical Association (JAMA)* concluded that the federal government should augment the use of physician assistants as physician substitutes, particularly in urban CHCs where the proportional use of physicians is higher. The article suggested that this could be accomplished by adequately funding Title VII programs. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 49 percent between 2004 and 2014. Title VII funding has provided a crucial pipeline of trained PAs to underserved areas. One way to assure an adequate supply of physician assistants practicing in underserved areas is to continue offering financial incentives to PA programs that emphasize recruitment and placement of PAs interested in primary care in medically underserved communities.

Despite the increased demand for PAs, funding has not proportionately increased for Title VII programs that educate and place physician assistants in underserved communities. Nor has Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2004 indicates an average annual increase of seven percent, a total increase of 256 percent over the past 20 years, as federal support has decreased.

#### **Recommendations on FY 2010 Funding**

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for FY 2010. For instance, while it is critical, now more than ever, to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration is inadequately funded. HRSA administers the “people” programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The Academy respectfully requests that Title VII health professions programs receive \$300 million in funding for FY 2010, including a minimum of \$7 million to support PA educational programs. Thank you for the opportunity to present the American Academy of Physician Assistants’ views on FY 2010 appropriations.

**Written Testimony  
from the  
American Association for Cancer Research (AACR)**

**Submitted to the House Appropriations Committee,  
Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies**

**May 1, 2009**

The American Association for Cancer Research (AACR) recognizes and expresses its thanks to the United States Congress for its longstanding support and commitment to funding cancer research. The recent large scale investment in research through the American Recovery and Reinvestment Act (ARRA) and the fiscal year (FY) 2009 budget will support current projects and provide for new efforts in the fight against cancer. These new efforts promise to yield innovative and potentially breakthrough approaches to understanding, preventing, treating and ultimately curing cancer. The full potential, however, will not be fully realized in a short one or two year period. Sustained, stable funding through regular appropriations will be necessary to allow researchers to make the key investments that will leverage the ARRA funds so that they both create jobs today and save lives tomorrow.

Unquestionably, the nation's investment in cancer research is having a remarkable impact. Cancer deaths in the United States have declined in recent years. This progress occurred in spite of an aging population and the fact that more than three-quarters of all cancers are diagnosed in individuals aged 55 and older. Yet this good news will not continue without stable and sustained federal funding for critical cancer research priorities.

The American Association for Cancer Research urges the United States House of Representatives to support President Obama's vision for doubling cancer research funding over the next five years and strongly support other biomedical research funding at the National Institutes of Health (NIH). AACR supports the \$6 billion for cancer research highlighted in the President's FY2010 budget outline, which would be best allocated to the National Cancer Institute. The AACR also supports the biomedical community's recommendation of a 7% increase for the NIH, which, when combined with President Obama's vision for cancer research, would fund NIH at a level of \$33.3 billion in FY 2010.

### **AACR: Fostering a Century of Research Progress**

The American Association for Cancer Research has been moving cancer research forward since its founding in 1907. Celebrating its 100<sup>th</sup> Annual Meeting, the AACR and its more than 28,000 members worldwide strive tirelessly to carry out its important mission to prevent and cure cancer through research, education, and communication. It does so by:

- fostering research in cancer and related biomedical science;
- accelerating the dissemination of new research findings among scientists and others dedicated to the conquest of cancer;
- promoting science education and training; and
- advancing the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world.

### **Facing An Impending Cancer “Tsunami”**

Over the past 100 years, enormous progress has been made toward the conquest of the nation’s second most lethal disease (after heart disease). Thanks to discoveries and developments in prevention, early detection, and more effective treatments, many of the more than 200 diseases called cancer have been cured or converted into manageable chronic conditions while preserving quality of life. The 5-year survival rate for all cancers has improved over the past 30 years to more than 65%. The completion of the doubling of the NIH budget in 2003 is bearing fruit as many new and promising discoveries are unearthed and their potential realized. However, there is much left to be done, especially for the most lethal and rarer forms of the disease.

We recognize that the underlying causes of the disease and its incidence have not been significantly altered. The fact remains that men have a 1 in 2 lifetime risk of developing cancer, while women have a 1 in 3 lifetime risk. The leading cancer sites in men are the prostate, lung and bronchus, and colon and rectum. For women, the leading cancer sites are breast, lung and bronchus, and colon and rectum. And cancer still accounts for 1 in 4 deaths, with more than half a million people expected to die from their cancer in 2009. Age is a major risk factor – this nation faces a virtual “cancer tsunami” as the baby boomer generation reaches age 65 in 2011. A renewed commitment to progress in cancer research through leadership and resources will be essential to avoid this cancer crisis.

### **Blueprint for Progress: NCI’s Strategic Objectives**

Basic, translational, and clinical cancer research in this country is conducted primarily through three venues – government, academia and the nonprofit sector, and the pharmaceutical/biotechnology industry. The Congress provides the appropriations for the National Institutes of Health and the National Cancer Institute (NCI) through which most of the government’s research on cancer is conducted. The NCI has developed documents and processes that describe and guide its priorities – established with extensive community input – for the use of these finite resources. “The NCI Strategic Plan for Leading the Nation” and “The Nation’s Investment in Cancer Research: An Annual Plan and Budget Proposal Fiscal Year 2010” are the recognized professional blueprints for what needs to be done to accelerate progress against cancer.

The American Association for Cancer Research and many in the cancer research community concur that if the NCI receives the increased investment of \$2.1 billion as proposed for FY 2010, the Director's proposed budget will enable the NCI to rebuild America's research infrastructure capacity and accelerate research progress in critical priority areas:

- Understanding the causes and mechanisms of cancer
- Accelerating progress in cancer prevention
- Improving early detection and diagnosis
- Developing effective and efficient treatments
- Understanding the factors that influence cancer outcomes
- Improving the quality of cancer care
- Improving the quality of life for cancer patients, survivors, and their families
- Overcoming cancer health disparities.

#### **Federal Investment for Local Benefit**

Over half of the NCI budget is allocated to research project grants that are awarded to outside scientists who work at local hospitals and universities throughout the country. More than 6,500 research grants are funded at more than 150 cancer centers and specialized research facilities located in 49 states. Over half the states receive more than \$15 million in grants and contracts to institutions located within their borders. This federal investment provides needed economic stimulus to local economies: on average, each dollar of NIH funding generated more than twice as much in state economic output in fiscal year 2007. Many AACR member scientists across the Nation are engaged in this rewarding work, and many have had their long-term research jeopardized by grant reductions caused by the flat and declining overall funding for the NCI since 2003. The recent increase in fiscal year 2009 appropriations and the funds from the American Recovery and Reinvestment Act of 2009 will help to revitalize America's research infrastructure; however, sustained and stable funding is critical to reap the benefits of this investment. Thus, the AACR supports the request in the President's budget proposal for \$6 billion in funding for cancer research in FY 2010 and his commitment to double funding for cancer research over the next five years and, thus, recommends a 20% increase in funding for the National Cancer Institute to enable it to continue and expand its important work.

#### **Understanding the Causes and Mechanisms of Cancer**

Basic research into the causes and mechanisms of cancer is at the heart of what the NCI and many of AACR's member scientists do. The focus of this research includes: investigating the underlying basis of the full spectrum of genetic susceptibility to cancer; identifying the influence of the macroenvironment (tumor level) and microenvironment (tissue level) on cancer initiation and progression; understanding the behavioral, environmental, genetic, and epigenetic causes of cancer and their interactions; developing and applying emerging technologies to expand our knowledge of risk factors and biologic mechanisms of cancer; and elucidating the relationship between cancer and other human diseases.

Basic research is the engine that drives scientific progress. The outcomes from this fundamental basic research – including laboratory and animal research in addition to population studies and the deployment of state-of-the-art technologies – will inform and drive the cancer research enterprise in ways and directions that will lead to unparalleled progress in the search for cures.

#### **Accelerating Progress in Cancer Prevention**

Preventing cancer is far more cost-effective and desirable than treating it. NCI's strategic plan supports research in: understanding and modifying behaviors that increase risk; reducing the influence of genetic and environmental risk factors; and interrupting the initiation of cancer through early medical intervention. A critical component of this multifaceted approach is the importance of widely disseminating and making accessible those evidence-based advances that have been shown to inform and motivate people toward healthy behaviors.

The NCI uses multidisciplinary teams and a systems biology approach to identify early events and how to modify them. More than half of all cancers are related to modifiable behavioral factors, including tobacco use, diet, physical inactivity, sun exposure, and failure to get cancer screenings. The NCI supports research to understand how people perceive risk, make health-related decisions, and maintain healthy behavior. Prevention is the keystone to success in the battle against cancer.

#### **Developing Effective and Efficient Treatments**

The future of cancer care is all about developing individualized therapies tailored to the specific characteristics of a patient's cancer. The NCI research in this area concentrates on: identifying the determinants of metastatic behavior; validating cancer biomarkers for prognosis, metastasis, treatment response, and progression; accelerating the identification and validation of potential cancer molecular targets; minimizing the toxicities of cancer therapy; and integrating the clinical trial infrastructure for speed and efficiency. The completion of the Human Genome Project has opened the door to the promise of personalized medicine.

#### **Overcoming Cancer Health Disparities**

Some minority and underserved population groups suffer disproportionately from cancer. Solving this issue will contribute significantly to reducing the cancer burden. The NCI's investments in this area include: studying the factors that cause cancer health disparities; working with underserved communities to develop targeted interventions; developing the knowledge base for integrating cancer services to the underserved; collaborating to implement culturally appropriate information dissemination approaches to underserved populations; and examining the role of health policy in eliminating cancer health disparities. One size does not fit all in cancer research – special populations require special treatment to achieve success.

### **Training and career development for the next generation of researchers**

Of critical importance to the viability of the long-term cancer research enterprise is supporting, fostering, and mentoring the next generation of investigators. The NCI historically devotes approximately four percent of its budget to multiple strategies to training and career development, including sponsored traineeships, a Medical Scientist Training Program, special set-aside grant programs and bridge grants for early career cancer investigators. Increased funding for these foundational opportunities is essential to retain the scientific workforce that is needed to continue the fight against cancer.

### **AACR's Initiatives Augment Support for the NCI**

The NCI is not working alone or in isolation in any of these key areas. NCI research scientists reach out to other organizations to further their work. The AACR is engaged in scores of initiatives that strengthen, support, and facilitate the work of the NCI. Just a few of AACR's contributions include:

- sponsoring the largest meeting of cancer researchers in the world, with more than 14,000 scientists, where 6,000 scientific abstracts featuring the latest basic, translational, and clinical scientific advances are presented;
- publishing more than 3,400 original research articles each year in six prestigious peer-reviewed scientific journals, including *Cancer Research*, the most frequently cited cancer journal;
- sponsoring the annual International Conference on Frontiers of Cancer Prevention Research, the largest such prevention meeting of its kind in the world;
- supporting the work of its Chemistry in Cancer Research Working Group;
- convening an AACR-FDA-NCI Think Tank on Clinical Biomarkers;
- hosting, with NCI, the Molecular Targets and Cancer Therapeutics Conference;
- sponsoring and supporting a Minorities in Cancer Research Council and a Women in Cancer Research Council;
- Conducting the scientific review and grants administration for the over \$100 million donated to Stand Up To Cancer;
- raising and distributing more than \$5 million in awards and research grants.

### **Stable, Sustained Increases in Research Funding**

Remarkable progress is being made in cancer research, but much more remains to be done. Cancer costs the nation more than \$219 billion in direct medical costs and lost productivity due to illness and premature death. Respected University of Chicago economists Kevin Murphy and Robert Topel have estimated that even a modest one percent reduction in mortality from cancer would be worth nearly \$500 billion in social value. Investments in cancer research stimulate the local economy today have huge potential returns in the future. Thanks to successful past investments, promising research opportunities abound and must not be lost. To maintain our research momentum, the American Association for Cancer Research (AACR) urges the United States House of Representatives to support a budget of \$33.3 billion for the National Institutes of Health, including \$6 billion for the National Cancer Institute.

Statement of the American Association for Dental Research  
before the  
House Subcommittee on Labor, Health and Human Services and Education

Presented by  
Marc Heft, D.M.D., Ph.D., Professor

Department of Oral & Maxillofacial Surgery  
Diagnostic Sciences and  
Director, Claude D. Pepper Center for Research  
on Oral Health in Aging at the  
University of Florida, Gainesville

Friday, May 1<sup>st</sup>, 2009

**Summary**

Dental research is concerned with increasing knowledge for the prevention, diagnosis, and treatment of diseases and disorders that affect the teeth, mouth, and jaws, and other systemic conditions. Dental health plays an important role in keeping people healthy throughout their lives. My testimony will cover accomplishments and the work that needs to be done in the following areas:

- Health disparities,
- Salivary diagnostics, and
- Oral cancer



### **Introduction**

Mr. Chairman and members of the Committee, I am Marc Heft, Professor at the Department of Oral & Maxillofacial Surgery Diagnostic Sciences and Director of the Claude D. Pepper Center for Research on Oral Health in Aging at the University of Florida. My testimony is on behalf of the American Association for Dental Research (AADR), a non-profit organization with over 4,000 individual members and 100 institutional members within the U.S. The AADR's mission is to advance research and increase knowledge for the improvement of oral health for all Americans.

I thank the committee for this opportunity to testify about the exciting advances in oral health science. Americans are living better and healthier lives into old age due to recent advances in health care, including dental care and oral health research thanks to the efforts of the National Institute of Dental and Craniofacial Research (NIDCR). NIDCR was formed in 1948 by the National Institutes of Health (NIH). They have conducted research, trained researchers, and disseminated health information in order to improve the health of Americans and make it possible for them to live longer and healthier.

On February 17<sup>th</sup> of this year, President Barack Obama signed the \$787 billion stimulus package known as the American Recovery and Reinvestment Act into law. This legislation will provide NIH with \$8.2 billion to conduct additional scientific research. On behalf of the AADR members and myself, I want to thank the committee for its past support and in particular for the funds contained in the stimulus package. The past investment in NIH has paid a dividend to taxpayers in the form of improved oral health.

### **Health Disparities**

One very challenging issue we face in this country is health disparities. We must learn more about the causes of cultural inequality among individual members of society in order to conduct more effective research.

The NIDCR's mission is to get as many young investigators as possible involved in oral health disparities research in order to come up with various methods of research to eliminate these disparities. They hope that this will improve the oral, dental and craniofacial health of diverse populations.

Health disparities are the persistent gaps between the health status of minorities and non-minorities in the United States. Despite continued advances in health care and technology, racial and ethnic minorities continue to have more disease, disability, and premature death than non-minorities. African Americans, Hispanics/Latinos, American Indians and Alaska Natives, Asian Americans, Native Hawaiians and Pacific Islanders, have higher rates of infant mortality, cardiovascular disease, diabetes, AIDS, cancer, and lower rates of immunizations and cancer screening.

There is debate about what causes health disparities between ethnic and racial groups. However, it is generally accepted that disparities can result from three main areas:

- From the personal, socioeconomic, and environmental characteristics of different ethnic and racial groups;
- From the barriers certain racial and ethnic groups encounter when trying to enter into the health care delivery system; and
- From the quality of health care different ethnic and racial groups receive.

These are all considered possible causes for disparities between racial and ethnic groups. However, most attention on the issue has been given to the health outcomes that result from differences in access to medical care among groups and the quality of care that various groups receive. Since a lot of scientific discoveries do not reach all people, there are disparities in the health and health care among various groups in the U.S. Even though data on racial and ethnic disparities are relatively widely available, data on socioeconomic health care disparities are collected less often.

The Health Disparities Research Program responds to the growing awareness that despite improvements in some oral health status indicators, the burden of disease is not evenly distributed across all segments of societies. The program supports research that explores the multiple and complex factors that may determine oral and craniofacial health, diseases, and conditions in disadvantaged and underserved populations. Funds go to a lot of different scientific approaches designed to reduce and eventually eliminate oral and craniofacial diseases and conditions in disadvantaged and underserved populations. The program supports both qualitative and quantitative approaches.

The NIDCR will support interventional research that will have a meaningful impact on caries, oral and pharyngeal cancer, and periodontal disease, and that will influence clinical practice, health policy, community and individual action and ultimately eliminate disparities in vulnerable people. The Institute will also fund health disparities interventional research beyond that conducted through the Centers for Research to Reduce Disparities in Oral Health program.

### **Salivary Diagnostics**

For many oral and systemic diseases, early detection offers the best hope for successful treatment. Oral and systemic diseases can be difficult to diagnose, involving complex clinical evaluation and/or blood and urine tests that are labor intensive, expensive, and invasive. Now, after many years of research, saliva is poised to be used as a non-invasive diagnostic fluid for a number of oral and systemic conditions. Saliva, a protective fluid of the oral cavity, combats bacteria and viruses that enter the mouth and serves as a first line of defense in oral and systemic diseases. It contains many compounds indicating a person's overall health and disease status and, like blood or urine, its composition may be

affected by a disease – therefore, saliva is a mirror of the body. Since saliva is easy to collect, it is a good alternative to using blood or urine for diagnostic tests.

The year 2008 has been an exciting one in the incremental development of salivary diagnostics. A consortium of NIDCR-supported scientists completed the first catalogue of the human salivary proteome, or the full set of 1,166 proteins present in saliva. This will help enable the future testing of saliva as a standard body fluid to detect early signs of disease. A team of NIDCR grantees currently assembled the first panel of salivary protein biomarkers to detect oral squamous cell carcinoma (OSCC). This is the most common form of the oral cancers.

Salivary diagnostic techniques have already been developed for and are being used to detect HIV. Saliva could be used as a potential monitor of disease progression in systemic disorders, including Alzheimer's disease, cystic fibrosis and diabetes. Specific protein markers in human saliva are being investigated that can be identified and quantified to provide an early, non-invasive diagnosis for even cancers distant from the oral cavity, such as; pancreatic and breast cancer. Getting a diagnosis used to entail making a trip to the doctor's office. The doctor's examination often required providing a blood and/or urine sample. Even though getting a diagnosis still requires a trip to the doctor's office, scientists are now identifying the genes and proteins that are expressed in the salivary glands that will help define the patterns and certain conditions under which these genes and proteins are expressed in the salivary glands. Building on this research, saliva will become a more commonly used diagnostic fluid.

### **Oral Cancer**

Oral cancer affects 38,000 Americans each year and 350,000 people worldwide. The death rate associated with this cancer is especially high due to delayed diagnosis. Oral cancer is any cancerous tissue growth located in the mouth. About two-thirds of oral cancers occur in the mouth and about one-third are found in the pharynx. On average, only 60 percent of those with the disease will survive more than five years. However, here again disparities play a role and only 35% of black men will survive five years. It occurs most in people over the age of 40 and affects more than twice as many men as women. Researchers are developing a Point of Care (POC) diagnostic system (real-time) for rapid onsite detection of saliva-based tumor markers. Early detection of oral cancer will increase survival rate, improve the quality of life of cancer patients, and will result in a significant reduction in health care costs.

Oral cancer forms in tissues of the lip or mouth. In 2008, approximately 22,900 new cases of oral cancer occurred in the United States. Oral cancer claimed roughly 5,390 deaths that year. It represents approximately 3% of all cancers. This, however, translates to 30,000 new cases every year in the United States. More than 34,000 Americans will be diagnosed with oral or pharyngeal cancer this year. It will cause over 8,000 deaths,

killing roughly 1 person per hour, 24 hours per day. Of those 34,000 newly diagnosed individuals, only half will be alive in 5 years. The death rate for oral cancer is higher than that of cancers such as cervical cancer, laryngeal cancer, thyroid cancer, or skin cancer. Worldwide, the problem is much greater, with over 400,000 new cases being found each year.

Survival rates can be calculated by different methods for different purposes. If oral cancer is caught when the disease has not spread beyond the original tumor site, the 5-year relative survival rate is 82 percent. However, half of oral cancers are not diagnosed until the cancer has spread to nearby tissues. At this stage, the 5-year relative survival rate drops to 53 percent. Those diagnosed when the cancer spread further, to distant organs, have only a 28 percent 5-year relative survival rate. It's important to detect oral cancer early when it can be treated more successfully. Typically, the earlier cancer is detected and diagnosed, the more successful the treatment, thus enhancing the survival rate.

### **Conclusion**

As you can see, Mr. Chairman, there are many research opportunities with an immediate impact on patient care that need to be pursued. A consistent and reliable funding stream for NIH overall, and NIDCR in particular, is essential for continued improvement in oral health of Americans. Oral cancer is one of the most expensive cancers to treat – the average cost for treating an advanced case is \$200,000. Overcoming cancer health disparities is one of the best opportunities we have for lessening the burden of cancer. But the burden of cancer is too often greater for the poor, ethnic minorities, and the uninsured than for the general population.

Mr. Chairman, a great amount of exciting research is underway, and the potential to improve oral health specifically and overall health in general, is significant. Therefore, we are requesting that NIDCR receive a fiscal year 2010 appropriation of \$440.9 million, not including the ARRA funding.

Thank you for the opportunity to testify. I would be pleased to respond to any questions you may have.

**Testimony of**

**Sharon P. Robinson  
President and CEO  
American Association of Colleges for Teacher Education**

**Representing the American Association of Colleges for Teacher Education**

**House Appropriations Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies**

**This testimony addresses the need for the federal government to invest more  
substantially in the preparation of PK-12 school personnel.**

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Sharon P. Robinson, Ed.D., President and CEO, American Association of Colleges for Teacher Education

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*Serving Learners*

April 30, 2009

The Honorable David Obey  
Chairman  
Subcommittee on Labor, HHS, and Education  
House Committee on Appropriations  
2314 Rayburn House Offices Building  
Washington, D.C. 20515

The Honorable Todd Tiahrt  
Ranking Member  
Subcommittee on Labor, HHS, and Education  
House Committee on Appropriations  
2369 Rayburn House Office Building  
Washington, D.C. 20515

Dear Chairman Obey and Ranking Member Tiahrt:

I want to extend my appreciation to you and your colleagues in Congress for your support of federal education programs. Your commitment makes a significant difference for the education of our millions of PK-12 and post-secondary students.

As you and your colleagues begin the FY 2010 appropriations process, **the American Association of Colleges for Teacher Education (AACTE) urges you to increase the federal government's investment in the preparation of professional educators.** While there are significant funds behind Title II of the No Child Left Behind Act in the Improving Teacher Quality State Grants, the vast majority of these funds, and other funds in Title II, go towards class size reduction and the professional development of practicing teachers. Equally important, though, is the initial preparation of teachers and other school personnel. And, in this respect, the federal government's investment, until very recently, has declined over the years. As this nation is in the midst of teacher retention and shortage crises, it is critical that the government responds with a plan that provides for systemic change.

There are several programs within the Department of Education intended to strengthen and improve educator recruitment and preparation efforts. We are working with program authorizers in Congress and staff within the agencies to ensure that these programs work in concert with each other. However, one of the key factors that prevents these programs from becoming levers for systemic change is their consistent under-funding. The cost of preparing school personnel is significant.

The primary federal program in this area is the Teacher Quality Partnership Grants (Title II, Higher Education Opportunity Act). During the reauthorization of the Higher Education Act we supported several changes to Title II of the bill that have resulted in a much stronger TQP

Sharon P. Robinson, Ed.D., President and CEO, American Association of Colleges for Teacher Education - 3 -

program. Under this program, these grants go to partnerships of institutions of higher education, high-need local educational agencies, and high-need K-12 schools to prepare teachers and other school personnel to effectively serve in the schools. The grants are particularly focused on strengthening the clinical component of preparation programs --- research has shown that pre-service clinical experiences are essential to preparing effective teachers and to teacher retention. Grants can be used to strengthen pre-baccalaureate preparation programs and/or to develop one-year master's degree level teaching residency programs. In exchange for receiving a living stipend during the residency, teachers would commit to teaching for at least three years in a shortage field in a high-need school. The residency programs are targeted to recruiting career-changers and recent college graduates. In these times of rising unemployment, these programs are ideal for those who have been laid off and are seeking a stable and rewarding new career. President Obama wrote the legislation for the teaching residency programs when he was a Senator on the HELP committee. During his presidential campaign and since his election he has stated that he wants to prepare 30,000 new educators through the residency programs.

**In order to meet that goal, and to provide sufficient support to the partnerships that carry out Teacher Quality Partnership Grants, we ask that you fund the TQP program at the \$150 million level in FY 10.** The TQP program received \$50 million in FY 09, and \$100 million in the stimulus package. This is a significant boost to the program which was funded in FY 08 at \$33 million. The \$150 million in FY 10 appropriations will maintain the current level of funding when the stimulus funding concludes.

Below you will find AACTE's recommendations for funding additional programs in FY 2010.

1. **Fund Teachers for a Competitive Tomorrow at the \$60 million level** – This program was authorized in the America Competes Act, and it is currently funded at \$2.18 million. This program and the TQP program are the only two federal education program directed targeted to higher education-based educator preparation programs. With the teacher shortage and retention crisis acutely felt in the math and science teaching fields, this program is a crucial piece of the response to ameliorate the teacher shortage challenges. This competitive grant program helps higher education institutions build baccalaureate and master's degree programs that allow students to major in STEM fields while working toward teacher certification.
2. **Fund the Transition to Teaching program at the \$60 million level** – This program, authorized in Title II of NCLB at the \$150 million level and currently funded at \$43.7 million, supports the development of teacher preparation programs suited for career-changers and others who enter teaching through non-traditional routes. Higher education institutions and other entities have used funds from this program to develop innovative preparation programs that accommodate the needs of a diverse educator candidate pool while ensuring that candidates are prepared to teach in today's K-12 classrooms.
3. **Fund the Troops-to-Teachers program at the \$25 million level** – Like Transition to Teaching, this program aims to attract teachers from another profession into the classroom. Troops-to-Teachers has been very successful at recruiting retired military into the teaching profession. By funding the program at \$25 million, this would almost double the government's investment in the program (currently at \$14.4 million) during a time in which there is higher military interest in entering the K-12 teaching ranks.

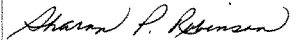
Sharon P. Robinson, Ed.D., President and CEO, American Association of Colleges for Teacher Education - 4 -

4. **Fund the IDEA Personnel Preparation program at the \$120 million level** – Currently funded at \$90.65 million, this program provides essential funds to prepare and develop special educators. Special education teachers, much like math and science teachers, are in high demand in the K-12 schools with the shortage being significant. With the wide breadth and increasing number of special need students there needs to be an adequate supply of teachers who can work with them to ensure student learning.
5. **Fund the Centers for Excellence Program at \$20 million.** This new program was authorized in Title II of the Higher Education Opportunity Act and is currently unfunded. Grants would support the strengthening of educator preparation programs at institutions that serve historically underrepresented populations.
6. **Fund the Teach to Reach Grant program at \$15 million.** This new program was authorized in Title II of the Higher Education Opportunity Act and is currently unfunded. Institutions of higher education would use grants to ensure that all of their teacher candidates were prepared to teach children with disabilities. Almost every K-12 classroom has students with learning, intellectual and/or physical disabilities. It is critical that every teacher is prepared with instructional skills that will assure that every child has the opportunity to learn.
7. **Fund the Graduate Fellowships to Prepare Faculty at Colleges of Education Program at \$15 million.** This new program was authorized in Title II of the Higher Education Opportunity Act and is currently unfunded. The current shortage of K-12 teachers in the math, science, special education and English language learners fields is directly correlated with the shortage of faculty at institutions of higher education who prepare teachers in these fields. This program would support doctoral students who intend to become faculty who prepare teachers in these shortage areas.

The American Association of Colleges for Teacher Education (AACTE) is a national voluntary association of higher education institutions and other organizations and is dedicated to ensuring the highest quality preparation and continuing professional development for teachers and school leaders. Our overarching mission is to enhance PK-12 student learning. Collectively, the AACTE membership prepares more than two-thirds of the new teachers entering schools each year in the United States.

If you or your staff have any questions, please do not hesitate to contact Jane West at (202) 293-2450 or [jwest@aacte.org](mailto:jwest@aacte.org). Thank you for your consideration of the perspective of AACTE and its membership of close to 800 private, state, and municipal colleges and universities--large and small--located in every state, the District of Columbia, the Virgin Islands, Puerto Rico, and Guam.

Sincerely,



Sharon P. Robinson, Ed.D.  
President and CEO



**Fiscal Year 2010 Appropriations for the Title VIII Nursing Workforce Development  
Programs, the National Institute of Nursing Research, and the Capacity for Nursing  
Students and Faculty Program  
U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and  
Education  
May 1, 2009**

Testimony submitted by:  
**American Association of Colleges of Nursing**  
One Dupont Circle, NW, Suite 530  
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The American Association of Colleges of Nursing (AACN) respectfully submits this statement highlighting funding priorities for nursing education and research programs in FY 2010. AACN represents over 640 schools of nursing at public and private universities and senior colleges with baccalaureate and graduate nursing programs that include over 270,000 students and 13,000 faculty members. These institutions are responsible for educating almost half of our nation's Registered Nurses (RNs) and all of the nurse faculty and researchers. Many of these nursing schools sponsor intensive research programs and training activities that are funded by the National Institute of Nursing Research (NINR).

**The Nationwide Nursing Shortage**

The United States is in the midst of a nursing shortage that has expanded over the last decade. The current economic downturn has led to a false impression that the nursing shortage is 'easing' in some parts of the country because hospitals are enacting hiring freezes and nurses are choosing to delay retirement. However, this trend is only temporary. More positions continue to open for RNs across the country and the shortage is projected to intensify as the baby-boomer population ages and the need for healthcare grows. On March 6, 2009, the U.S. Bureau of Labor Statistics (BLS) reported that the health care sector of the economy is continuing to grow, despite significant job losses in nearly all major industries. Hospitals, long-term care facilities, and other ambulatory care settings added 27,000 new jobs in February 2009, a month when 681,000 jobs were eliminated across the country. As the largest segment of the healthcare workforce, RNs likely will be recruited to fill many of these new positions. Moreover, according to the latest projections from the BLS, more than one million new and replacement nurses will be needed by 2016. Unless we act *now*, this shortage will further jeopardize patient access to quality care.

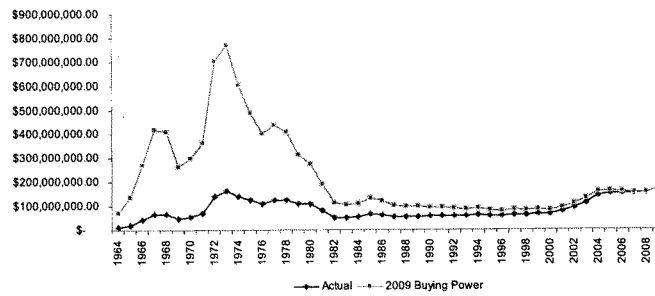
Nursing and economic research clearly indicate that today's shortage is far worse than those of the past. The current supply and demand for nurses demonstrates two distinct challenges. First, due to the present and looming demand for health care by American consumers, the supply is not growing at a pace that will adequately meet long-term needs, including the demand for primary care which is often provided by Advanced Practice Registered Nurses (APRNs). This is further compounded by the number of nurses who will retire or leave the profession in the near future, ultimately reducing the supply of nurses. Second, the supply of nurses nationwide is stressed due to an ongoing shortage of nurse faculty. The nurse faculty shortage continues to inhibit nursing schools from educating the number of nurses needed to meet the demand. According to AACN, 49,948 qualified applicants were turned away from baccalaureate and graduate nursing programs in 2008 primarily due to a lack

of faculty. Of those potential students, nearly 7,000 were students pursuing a master's or doctoral degree in nursing, which is the education level required to teach.

### Nursing Workforce Development Programs: A Proven Solution

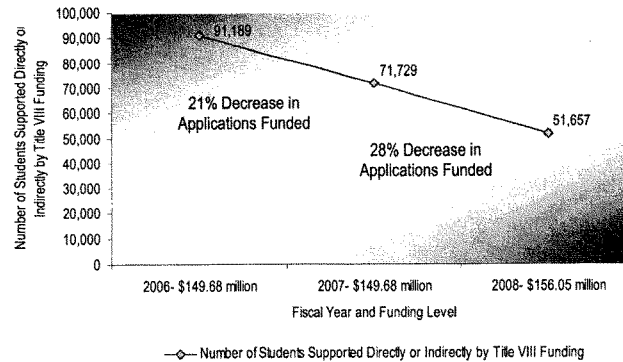
Over the last 45 years, Congress has used the Title VIII authorities as a mechanism to address nursing shortages. When the need for nurses was great, higher funding levels were appropriated. In 1973, Congress provided \$160.61 million to the Title VIII programs, the highest level of funding prior to FY 2009 (\$171.03 million). Adjusting for inflation to address the 36-year difference, \$171.03 million in 1973 dollars would be approximately \$820 million in current dollars (see Figure 1). More recently, slow rising funding levels between FY 2006 and FY 2008 for Title VIII, coupled with inflation and rising educational costs, have greatly decreased the purchasing power of these programs, resulting in a 43% decrease in the number of nurses supported by the programs (see Figure 2).

Figure 1: Historical Funding for Title VIII Nursing Workforce Development Programs (in millions) and Adjusted for Inflation



Source: Health Resources and Services Administration (HRSA), Division of Nursing, 2008 & U. S. Bureau of Labor Statistics, Inflation Calculator, 2009.

Figure 2: Nurses and Nursing Students Supported by Title VIII: FY 2006-2008



Source: Division of Nursing, Health Resources and Services Administration, 2006, 2007, 2008.

Given the projections that the nursing shortage will continue to worsen over the next decade and the need to increase the primary care workforce will grow, more must be done to help alleviate the barriers that have significantly slowed the growth of the RN and APRN workforce. **Therefore, AACN respectfully requests \$215 million for Title VIII Nursing Workforce Development Programs in FY 2010**, an additional \$43.97 million over the FY 2009 level. Based on the number of students supported in previous years, this funding could potentially support 71,000 nurses and nursing students. New monies would expand nursing education, recruitment, and retention efforts to help resolve all aspects contributing to the shortage.

*An Overview of the Title VIII Programs: An Effective Approach to Address the Shortage*

Over the last 45 years, the Nursing Workforce Development Programs have supported hundreds of thousands of nurses and nursing students. The Title VIII programs award grants to nursing education programs, as well as provide direct support to nurses and nursing students through loans, scholarships, traineeships, and programmatic grants.

The Nursing Workforce Development Programs are effective and meet their authorized mission. In a 2009 survey by AACN, 1,501 Title VIII student recipients reported that these programs played a critical role in funding their nursing education. An overwhelming number of respondents (92.7%), reported that Title VIII paid for a portion of their tuition and, of those students, approximately 11% reported their tuition was paid in full. While millions of Americans are struggling during this economic downturn and thousands of students need to obtain student loans for their education, federal support is greatly appreciated and needed. The nursing students responding to this study expressed overwhelming gratitude for the funding they receive through Title VIII. Nursing remains an attractive and rewarding career with over 140,000 current vacant positions and according to the U.S. BLS over 587,000 new nursing positions becoming available by 2016. Providing support for Title VIII is the key to filling these vacant positions and, in turn, improving the quality of health care.

*Title VIII Programs at a Glance*

*Advanced Education Nursing (AEN) Grants, AEN Traineeships, and Nurse Anesthetist Traineeships (Sec. 811)* prepare our nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, and other nurse specialists requiring advanced education. In FY 2008, 18,228 nurses were supported.

*Workforce Diversity Grants (Sec. 821)* prepare students from disadvantaged backgrounds to become nurses. This program awards grants and contract opportunities to nursing schools, nurse-managed health centers, and other entities looking to increase access to nursing education for disadvantaged students, including racial and ethnic minorities who are under-represented among RNs. In FY 2008, these grants supported 18,741 students and helped graduate 621 nurses.

*Nurse Education, Practice, and Retention Grants (Sec. 831)* supported nearly 6,000 nursing students and helped graduate 1,700 nurses in FY 2008 by assisting schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and health care facilities strengthen nursing programs by offering:

- Education Grants to expand enrollments in baccalaureate nursing programs, develop programs to enhance mentoring and specialty training, and provide new technology.
- Practice Grants to expand practice arrangements in non-institutional settings to improve primary

health care in medically underserved communities, provide care for underserved populations, and develop cultural competencies.

- Retention Grants to maintain the Career Ladder program by assisting individuals with career advancement via training and education, and enhancing patient care delivery systems by increasing collaboration and communication among nurses and other healthcare professionals.

*Nurse Loan Repayment and Scholarship Programs (Sec. 846)* support students and new graduates by offering a repayment program, covering up to 85% of nursing student loans in return for at least three years of practice in a designated healthcare facility with a critical shortage of nurses. The scholarship program offers full-time nursing students the opportunity to apply for scholarship funds in return for a two- year commitment to work in a healthcare facility with a critical shortage of nurses. In FY 2008, this program supported 604 students and recent graduates.

*Nursing Student Loan Program (Sec. 835)* is a revolving fund that provides undergraduate and graduate nursing students with financial need up to \$13,000 per year at a 5% interest rate. The repayment period is 10 years and new students are supported as existing loans are repaid. This program has not received additional appropriations since 1983.

*Nurse Faculty Loan Program Grants (Sec. 846a)* is the only Title VIII program solely dedicated to educating the next generation of nurse faculty. Participating students must agree to teach at a nursing school in exchange for cancellation of up to 85% of their educational loans, plus interest, over four years. In FY 2008, this program supported 729 students and helped graduate 401 future nurse faculty.

*Comprehensive Geriatric Education Grants (Sec. 855)* are awarded to eligible entities such as nursing schools or healthcare facilities to educate nurses to provide better healthcare services for the elderly.

#### **NINR: Supporting Health Promotion & Disease Prevention**

As the scientific and research nucleus for nursing science, the NINR funds research that establishes the scientific basis for health promotion, disease prevention, and high quality nursing care activities for individuals, families, and populations. NINR is one of the 27 Institutes and Centers at the National Institutes of Health (NIH). Often working collaboratively with physicians and other researchers, nurse scientists are vital in setting the national research agenda. While medical research focuses on curing diseases, nursing research is conducted to *prevent* disease. The four strategic areas of emphasis for research at NINR are:

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>▪ Promoting Health and Preventing Disease</li> <li>▪ Improving Quality of Life</li> </ul> | <ul style="list-style-type: none"> <li>▪ Eliminating Health Disparities</li> <li>▪ Setting Directions for End-of-Life Research</li> </ul> |
|--|---|

The science advanced at NINR is integral to the future of the nation's healthcare system. Through grants, research training, and interdisciplinary collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. With a renewed national priority on utilizing cost effective treatment modalities and preventive interventions, NINR has developed research programs in these areas:

*Comparative Effectiveness Research* has been an NINR funding priority for many years.

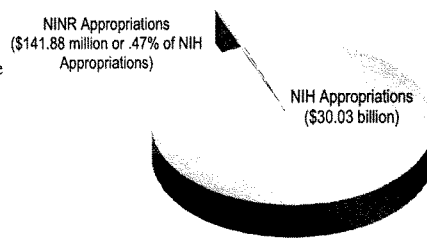
Comparative effectiveness research demonstrates how prevention strategies or interventions can impact system-wide savings. At a time when healthcare consumers and reformers are

seeking quality care focused on prevention that is affordable and accessible by all, comparative effectiveness research is a critical area of inquiry.

*Promoting Health and Preventing Disease* is vital considering that more than 1.7 million Americans die each year from chronic diseases. Nurse researchers focus on investigating wellness strategies to prevent these chronic diseases. A healthcare system which promotes prevention promises to be a major focus of health reform, and NINR is a leader in funding scientific research to discover optimal prevention methods.

NINR's FY 2009 funding level of \$141.88 million is approximately 0.47% of the overall \$30.03 billion NIH budget (see Figure 3). Spending for nursing research is a modest amount relative to the allocations for other health science institutes and for major disease category funding. For NINR to adequately continue and further its mission, the institute must receive additional funding. Cuts in funding have impeded the institute from supporting larger comprehensive studies needed to advance nursing science and improve the quality of patient care.

Figure 3: FY 2009 NINR Appropriations as a Portion of the NIH Budget



**Therefore, AACN respectfully requests \$178 million for the National Institute of Nursing Research**, an additional \$36.12 million over the FY 2009 level. Considering that NINR presently allocates 7% of its budget to training that helps develop the pool of nurse researchers, additional funding would support NINR's efforts to prepare faculty researchers needed to educate new nurses.

**The Capacity for Nursing Students and Faculty Program, Section 804 of the Higher Education Opportunity Act of 2008 (P.L. 110-315).**

According to AACN (2009), the major barriers to increasing student capacity in nursing schools are insufficient numbers of faculty, admission seats, clinical sites, classroom space, clinical preceptors, and budget constraints. The *Capacity for Nursing Students and Faculty Program*, a recently passed section of the *Higher Education Opportunity Act of 2008*, offers capitation grants (formula grants based on the number of students enrolled/or matriculated) to nursing schools allowing them to increase the number of students. **AACN respectfully requests \$50 million for this program in FY 2010.**

**Conclusion**

AACN acknowledges the fiscal challenges within which the Subcommittee and the entire Congress must work. However, the Title VIII authorities provide a dedicated, long-term vision for educating the new nursing workforce and the next cadre of nurse faculty. The National Institute of Nursing Research invests in developing the scientific basis for quality nursing care. The *Capacity for Nursing Students and Faculty Program* will allow schools to increase student capacity. To be effective these programs must receive additional funding. **AACN respectfully requests \$215 million for Title VIII programs, \$178 million for NINR, and \$50 million for the Capacity for Nursing Students and Faculty Program in FY 2010.** Additional funding for these programs will assist schools of nursing to expand their educational and research programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our healthcare system.



AMERICAN ASSOCIATION OF  
COLLEGES OF OSTEOPATHIC MEDICINE

**Testimony of Stephen C. Shannon, DO, MPH**  
**President and Chief Executive Officer**  
**American Association of Colleges of Osteopathic Medicine**  
**301-968-4142**  
**sshannon@aacom.org**

**Concerning Department of Health and Human Services Appropriations for  
Fiscal Year 2010**  
**Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**  
**House Committee on Appropriations**  
**Submitted for the Record**  
**April 30, 2009**

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to submit this testimony in support of increased funding in fiscal year (FY) 2010 for the Title VII health professions education programs, the National Health Service Corps, the National Institutes of Health, and the Agency for Healthcare Research and Quality. AACOM represents the administrations, faculty, and students of the nation's 25 colleges of osteopathic medicine and three branch campuses that offer the doctor of osteopathic medicine degree. Today, more than 15,500 students are enrolled in osteopathic medical schools. Nearly one in five U.S. medical students is training to be an osteopathic physician, a ratio that is expected to grow to one in four by 2019.

**Title VII**

The health professions education programs, authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), support the training and education of health practitioners to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces. Title VII and Title VIII nurse education programs are the only federal programs designed to train clinicians in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

According to HRSA, an additional 30,000 health practitioners are needed to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care, and a growing, aging population, these needs strain an already fragile health care system. AACOM recommends \$330 million in FY 2010 for the Title VII programs. Investment in these programs, including the Training in Primary Care Medicine and Dentistry Program, the Health Careers Opportunity Program, and the Centers of Excellence, is necessary to address the primary care workforce shortage. Such an

U.S. House of Representatives  
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investment will help sustain the health workforce expansion supported by the American Recovery and Reinvestment Act (ARRA) and restore funding to critical programs that suffered drastic funding reductions in FY 2006 and remain well below FY 2005 levels.

#### National Health Service Corps

Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. Through scholarships and loan repayment, HRSA's National Health Service Corps (NHSC) supports the recruitment and retention of primary care clinicians to practice in underserved communities. The NHSC is comprised of more than 4,000 clinicians, with more than half working in community health centers. Growth in HRSA's Health Center Program must be complemented with increases in the recruitment and retention of primary care clinicians to ensure adequate staffing. ARRA funding for the NHSC is vital in this regard, and additional investment will be necessary to sustain the progress once the ARRA funding period ends. AACOM recommends \$235 million in FY 2010 for the National Health Service Corps, the amount authorized under the Health Care Safety Net Amendments of 2002.

#### National Institutes of Health

Research funded by the National Institutes of Health (NIH) leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases as well as disease prevention. These efforts improve our nation's health and save lives. The NIH funding under the ARRA will produce more high quality research. To seize the momentum created by the ARRA and maintain a robust research agenda, further investment will be needed. AACOM recommends \$33.35 billion in FY 2010 for the NIH.

In today's increasingly demanding and evolving medical curriculum, there is a critical need for more research geared toward evidence-based osteopathic medicine. AACOM believes that it is vitally important to maintain and increase funding for biomedical and clinical research in a variety of areas related to osteopathic principles and practice, including osteopathic manipulative medicine and comparative effectiveness. In this regard, AACOM encourages support for the NIH's National Center for Complementary and Alternative Medicine to continue fulfilling this essential research role.

#### Agency for Healthcare Research and Quality

The Agency for Healthcare Research and Quality (AHRQ) supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our nation's health and health care. The incremental increases for AHRQ's Effective Health Care Program in recent years, as well as the funding provided to AHRQ in the ARRA, will help AHRQ generate more comparative effectiveness research and expand the infrastructure needed to increase capacity to produce this evidence. More investment is needed, however, to fulfill AHRQ's mission and broader research agenda. AACOM recommends \$405 million in FY 2010 for AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives.

AACOM greatly appreciates the support of the Subcommittee for these funding priorities in an ever increasing competitive environment and is grateful for the opportunity to submit its views. AACOM looks forward to continuing to work with the Subcommittee on these important matters.



American Association of  
Colleges of Pharmacy  
*Discover • Learn • Care • Improve Health*



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**United States Senate/House Appropriations Subcommittee on Labor, Health and Human Services, and Education**

**Public Witness Testimony for the Record**  
**Regarding FY 2010 funding levels for programs of interest to U.S. colleges and schools of pharmacy**

AACP and its member colleges and schools of pharmacy appreciate the continued support of the U.S. House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education. Our nation's 111 accredited colleges and schools of pharmacy are engaged in a wide-range of programs supported by grants and funding administered through the agencies of the Department of Health and Human Services (HHS) and the Department of Education. We also understand the difficult task you face annually in your deliberations to do the most good for the nation and remain fiscally responsible to the same. AACP respectfully offers the following recommendations for your consideration as you undertake your deliberations.

**US DEPARTMENT OF HEALTH AND HUMAN SERVICES SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY**

**Agency for Healthcare Research and Quality (AHRQ)**

**AACP supports the Friends of AHRQ recommendation of \$405 million for AHRQ programs in FY10.**

Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Academic pharmacy researchers are working to develop a sustainable health services research effort among faculty with AHRQ grant support. As partners in the AHRQ Effective Healthcare programs (CERTs, DeCIDE), pharmacy faculty researchers improve the effectiveness of healthcare services. Some of this research will take place through the development of practice-based research networks focused on improving the medication use process.

- Last fall, the Agency for Healthcare Research and Quality (AHRQ) expanded its Centers for Education and Research on Therapeutics (CERTs) program by awarding \$41.6 million over the next four years for a new coordinating center, 10 research centers and four new centers receiving first-time funding. The University of Illinois at Chicago (UIC) College of Pharmacy joins the 13 CERTs program centers in efforts to conduct research and provide education that advances the optimal use of therapeutics.  
<http://www.aacp.org/news/academicpharmnow/Documents/MarApr%202008%20APN.pdf>

**AHRQ (cont.)**

- Pharmacy faculty researchers, supported by AHRQ grant HS016097, determined that children who are prescribed medications related to their diagnosis of attention deficit/hyperactivity disorder were not at increased risk for hospitalization for cardiac events. The results of this research will be presented in a web conference sponsored by AHRQ and APhA on May 1, 2009.

**Centers for Disease Control and Prevention (CDC)****AACP supports the CDC Coalition recommendation of \$8.6 billion for CDC core programs in FY10.**

The educational outcomes of a pharmacist's education include those related to public health. When in community-based positions, pharmacists are frequently providers of first contact. The opportunity to identify potential public health threats through regular interaction with patients provides public health agencies such as the CDC with on-the-ground epidemiologists. Pharmacists support the public health system through the risk identification of patients seeking medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research in areas such as immunization delivery, integration of pharmacogenetics in the pharmacy curriculum and inclusion of pharmacists in emergency preparedness. Information from the National Center for Health Statistics (NCHS) is essential for faculty engaged in health services research and for the professional education of the pharmacist.

- Grace Kuo, CDC-supported member of the faculty at the University of California, San Diego, is engaged in research aimed at improving the safety of medication use in primary care settings. 7K08HS014552-04
- Jeanine Mount, CDC-supported member of the faculty at the University of Wisconsin, is engaged in research to determine how pharmacists can be better utilized to increase the vaccination rates across our nation. 1U01IP000060-01

**Health Resources and Services Administration (HRSA)****AACP supports the Friends of HRSA recommendation of \$8.5 billion.**

HRSA is a federal agency with a wide-range of policy and service components. Faculty at colleges and schools of pharmacy are integral to the success of many of these. Colleges and schools of pharmacy are the administrative units for interprofessional and community-based linkages programs including geriatric education centers and area health education centers. Pharmacy faculty are supported in their research efforts regarding rural health issues through the Office of Rural Health Policy. Pharmacy students benefit from diversity program funding including Scholarships for Disadvantaged Students.

**Office of Pharmacy Affairs****AACP recommends a program funding of \$5 million for FY10 for the Office of Pharmacy Affairs.**

AACP member institutions are actively engaged in Office of Pharmacy Affairs (OPA) efforts to improve the quality of care for patients in federally-qualified health centers and entities eligible to participate in the 340B drug discount program. The success of the HRSA Patient Safety and Clinical Pharmacy Collaborative is a direct result of past OPA actions linking colleges and schools of pharmacy with federally-qualified health centers. [www.hrsa.gov/patientsafety](http://www.hrsa.gov/patientsafety) The result of these links has been the establishment of medical homes that improve health outcomes for underserved and disadvantaged patients

**HRSA****OPA (cont.)**

through the integration of clinical pharmacy services. The Office of Pharmacy Affairs would benefit from a direct line-item appropriation so that public-private partnerships aimed at improving the quality of care provided at federally qualified health centers can be sustained and expanded.

**Poison Control Centers**

Colleges and schools of pharmacy are supported by HRSA grant funding for the operation of nine of the 42 poison control centers administered by HRSA.

- Jill E. Michels, faculty member from the University of South Carolina – South Carolina College of Pharmacy (USC), and the Palmetto Poison Center (PPC) were awarded a \$310,000 grant from HRSA. The PPC is housed at the College of Pharmacy and serves all 46 counties in South Carolina receiving over 37,000 calls per year for information and advice. The PPC provides services free-of-charge to the public and health professionals 24 hours-a-day, 365 days-a-year. A recent USC study found that for every dollar spent on the Palmetto Poison Center, more than \$7 were saved in unnecessary healthcare costs, including emergency room and physician visits, ambulance services, and unnecessary medical treatments.  
<http://poison.sc.edu/about.html>

**Bureau of Health Professions (BHP)****AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of \$550 million for Title VII and VIII programs in FY10.**

AACP member institutions are active participants in BHP programs. Two colleges of pharmacy are current grantees in the Centers of Excellence program (Xavier University - Louisiana, University of Montana). This program focuses on increasing the number of underserved individuals attending health professions institutions. Colleges and schools of pharmacy are also part of Title VII interprofessional and community-based linkages programs including Geriatric Education Centers and Area Health Education Centers. These programs are essential for creating the educational approaches necessary for the Institute of Medicine's recommendations of improving quality through team-based, patient-centered care.

**Office of Telehealth Advancement**

Technology is an important component for improving healthcare quality and maintaining or increasing access to care. Colleges and schools of pharmacy utilize technology to increase the reach of education to aspiring and current professionals.

- Massachusetts College of Pharmacy and Health Sciences - Worcester Campus Distance Learning Initiative-Phase II. Grant support for this program will allow the expansion of health profession education programs throughout Massachusetts and New Hampshire.  
[http://hrsa.gov/telehealth/grantedirectory/overview\\_ma.htm](http://hrsa.gov/telehealth/grantedirectory/overview_ma.htm)
- North Dakota State University College of Pharmacy, Nursing, and Allied Sciences uses grant funding to maintain access to pharmacy services in rural, underserved areas of North Dakota. This program helps over 40,000 rural citizens maintain access to pharmacy services and also supports rural hospital pharmacies.  
[http://hrsa.gov/telehealth/grantedirectory/overview\\_nd.htm](http://hrsa.gov/telehealth/grantedirectory/overview_nd.htm)

**Food and Drug Administration (FDA)****AACP recommends a funding level of \$3 billion for FDA programs in FY10.**

Academic pharmacy is working with the FDA to fulfill its strategic goals and the responsibilities assigned to the agency through the Food and Drug Administration Amendments Act. The FDA sees the colleges and schools of pharmacy as essential partners in assuring the public has access to a healthcare professional well versed in the science of safety. Pharmacy faculty and students provide the FDA with a “go-to” group to create the educational outcomes that will empower patients to be members of the healthcare team. The FDA also supports pharmacy schools working to improve the drug manufacturing process.

- Carole L. Kimberlin, a professor, and Almut G. Winterstein, an assistant professor at the University of Florida College of Pharmacy Department of Pharmaceutical Outcomes and Policy, received a one-year \$184,229 award from the Food and Drug Administration to conduct an evaluation of Consumer Medication Information leaflets on selected prescription medications from community pharmacies throughout the United States.
- Thomas C. Dowling’s research, “Evaluation of Biopharmaceutics Classification System Class 3 Drugs for Possible Biowaivers,” is supported by an FDA grant.
- The FDA-supported National Institute of Pharmaceutical Technology and Education (NIPTE) is funding research at the University of Connecticut focused on the development of freeze dried products.

**National Institutes of Health (NIH)****AACP supports the Ad Hoc Group for Medical Research recommendation of \$32.4 billion for FY10.**

Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the research spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In 2008, pharmacy faculty researchers received more than \$260 million in grant support from the NIH. AACP member institutions are concerned, as are other health professions education organizations, of the need to increase the number of biomedical researchers. This concern is supported by an initial grant funding success rate that has never been more than 30 percent in the last decade. <http://report.nih.gov/NIHDatabook/Charts/SlideGen.aspx?chartId=126&catId=13>

- Researchers at the University of Illinois at Chicago College of pharmacy have received a \$1.7 million five-year federal grant to develop a new approach to treat brain tumors. The novel approach stabilizes the drug and provides better control of the time and location of its activity, thereby reducing its side effects.
- University of Nebraska Medical Center (UNMC) received \$10.6 million from the National Center for Research Resources (NCRR) to research nanomedicine, drug delivery, therapeutics and diagnostics. UNMC researcher, Dr. Alexander V. Kabanov, is the principal investigator on the \$10.6 million COBRE (Centers for Biomedical Research Excellence) grant, which will be awarded by the NIH/NCRR over the next five years.
- Dr. Maria Croyle, associate professor of pharmaceutics at The University of Texas at Austin College of Pharmacy, has received \$2.6 million from NIH to develop a vaccine against Ebola virus infection.

**NIH (cont.)**

- As part of the National Institutes of Health (NIH) funding for the new NIH Roadmap Epigenomics Program, Dr. Rihe Liu, associate professor at the University of North Carolina at Chapel Hill Eshelman School of Pharmacy, received a technology development grant to support the advancement of innovative technologies that have the potential to transform the way that epigenomics research can be performed in the future.
- A project funded by the National Institute of General Medical Sciences (NIGMS) takes computer-aided drug design to the next level with the help of a University of Michigan College of Pharmacy professor.
- Fourteen additional universities were awarded the Clinical and Translational Science Award (CTSA) in May 2008. Five colleges of pharmacy are included in this group and will play significant collaborative roles with the new consortium members as the NIH provides \$533 million over five years to help enable researchers to provide new treatments more efficiently and effectively to patients.
- Dr. Laurence H. Hurley, professor of pharmaceutical sciences at The University of Arizona College of Pharmacy, is one of 38 scientists to receive the 2009 NIH EUREKA grant.

**US DEPARTMENT OF EDUCATION SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY**

**AACP supports the recommendation of the Student Aid Alliance that the:**

1. **Perkins Loan Program Federal Capital Contribution should be increased to the newly reauthorized level of \$300 million and loan cancellations should be increased to \$125 million.**
2. **Pell Grant maximum be increased to \$5500.**
3. **Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP) should be increased to the authorized level of \$400 million.**
4. **Graduate level programs should be increased to \$77 million.**

**AACP recommends a funding level of \$140 million for the Fund for the Improvement of Post Secondary Education (FIPSE).**

The Department of Education supports the education of healthcare professionals by:

- assuring access to education through student financial aid programs;
- supporting educational research allows faculty to determine improvements in educational approaches; and
- maintaining the quality of higher education through the approval of accrediting agencies.

AACP actively supports increased funding for undergraduate student financial assistance programs. Admission to into the pharmacy professional degree program requires at least two years of undergraduate preparation. Student financial assistance programs are essential to assuring colleges and schools of pharmacy are accessible to qualified students. Likewise, financial assistance programs that support graduate education are an important component of creating the next generation of scientists and educators that both our nation and higher education depend on.

**Testimony of William R. Green, Ph.D., The American Association of Immunologists,  
Submitted to the House Appropriations Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies, Regarding the Fiscal Year (FY) 2010 Budget  
for the National Institutes of Health – May 1, 2009**

[William R. Green, Ph.D.: (603) 650-1200; [william.r.green@dartmouth.edu](mailto:william.r.green@dartmouth.edu)]

The American Association of Immunologists (AAI), a not-for-profit professional society representing more than 6,000 of the world's leading experts on the immune system, appreciates having this opportunity to submit testimony regarding Fiscal Year (FY) 2010 appropriations for the National Institutes of Health (NIH). The vast majority of AAI members - research scientists and physicians who work in academia, government, and industry - depend on NIH funding to advance their work and the broader field of immunology.<sup>1</sup> With approximately 83% of NIH's ~\$29 billion budget awarded to scientists throughout the United States and around the world, NIH funding advances not only immunological and biomedical research, but also regional and national economies.<sup>2</sup>

**The scope and importance of immunology**

From infectious diseases including influenza, HIV/AIDS, malaria, smallpox, and the common cold, to chronic diseases like cancer, diabetes, rheumatoid arthritis, asthma, and lupus, the immune system plays a central role in human and animal health.<sup>3</sup> Whether protecting the body from disease - or causing it (as in the case of autoimmune disease or the rejection of transplanted organs)<sup>4</sup> - the immune system is critical to maintaining individual human life and pivotal to community and global public health.<sup>5</sup> Prevention,

<sup>1</sup> The majority of AAI members receive grants from the National Institute of Allergy and Infectious Diseases (NIAID) or the National Cancer Institute (NCI); some receive grants from other NIH institutes, including the National Institute on Aging (NIA) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

<sup>2</sup> NIH funding supports "almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every state and around the world." NIH Website: <http://www.nih.gov/about/NIHOverview.html> (April 28, 2009)

<sup>3</sup> Research on the immune system is also of enormous benefit to pets and livestock.

<sup>4</sup> The immune system works by recognizing and attacking "foreign invaders" (e.g., bacteria and viruses) inside the body and by controlling the growth of tumor cells. A healthy immune system can protect its human or animal host from illness or disease either entirely - by attacking and destroying the virus, bacterium, or tumor cell - or partially, resulting in a less serious illness. It is also responsible for the rejection responses observed following transplantation of organs or bone marrow. The immune system can malfunction, causing the body to attack itself, resulting in an "autoimmune" disease, such as Type 1 diabetes, multiple sclerosis, or rheumatoid arthritis.

<sup>5</sup> NIH funds research "on 'neglected infectious diseases' such as malaria, tuberculosis, and a host of tropical diseases—diseases that are most prevalent in low-income countries, and that are insufficiently researched by the drug industry." Testimony of Ron Pollack, Executive Director, Families USA, before the House Energy and Commerce Subcommittee on Health, hearing on "Treatments for an Ailing Economy: Protecting Health Care Coverage and Investing in Biomedical Research," November 13, 2008, page 4.

treatments, and cures depend on our understanding of a scientific field that is relatively new: although the first vaccine was developed in 1798 (to protect against smallpox), most of our basic understanding of the immune system has developed in the past 30-40 years, making immunology ripe for the many new discoveries that are unfolding every day.

Emerging areas in immunology involve understanding the immune response to environmental threats, to pathogens that threaten to become the next pandemic, and to man-made and natural infectious organisms that are potential agents of bioterrorism (including plague, smallpox, and anthrax). For all of these urgent needs, basic research on the immune system provides a crucial foundation for the development of diagnostics, vaccines, and therapeutics.

#### **Recent immunological discoveries**

Immunologists are making significant advances in the development of treatments and vaccines against pernicious viruses such as influenza strains and HIV. Recently, commonalities were identified among the viruses causing seasonal flu, avian flu, and the 1918 pandemic flu, indicating that the same antibodies will neutralize them. Such antibodies were generated and could be developed for therapeutic use in the case of a flu outbreak. In studies on HIV, immunologists have also identified a unique small antibody fragment that is able to stop a broad range of HIV strains from entering their target cells. This offers hope for a therapy against HIV, which mutates too quickly to be responsive to most traditional vaccine strategies.

An explosion of research has followed the major recent discovery of the central role of the inflammasome in immunity. Inflammasomes are broadly important molecular complexes within our cells that sense infections, environmental pollutants, and other "danger" signals and control the activation of the pro-inflammatory, hormone-like molecules interleukin-1 and interleukin-18. Although it may help protect against infection, inflammasome-induced interleukin-1 has also been found to be a key "offender" in many inflammatory and autoimmune diseases. Inhibitors of these inflammatory molecules have already demonstrated significant clinical efficacy in autoimmune diseases, gout, and inherited periodic fever syndromes and are being investigated in other illnesses given the potential of the inflammasome to be relevant to almost any type of disease.

Immunologists have made important progress against the increasing prevalence of childhood peanut allergies by developing a mouse model that is being used to study the basis of this allergy. They have also identified a possible treatment course that might reverse the resultant anaphylaxis that can be life-threatening.

Immunologists are also focusing research efforts in the area of cancer vaccines. Novel delivery strategies, to effectively present tumor antigens or portions of the tumors themselves, have allowed the redirection of the immune system to attack cancerous cells within the body. Other strategies that manipulate molecules (including the inhibitory receptor CTLA4) on immune cells have shown remarkable clinical promise for melanoma and prostate cancer. In addition, our understanding of how tumors evade and suppress immunity is evolving, providing new options for therapy, such as altering the function of T-regulatory cells, which normally suppress immunity and thereby promote tumor growth.

Immunologists have also made important progress in understanding autoimmune disease by discovering that furin, a catalytic enzyme, prevents some forms of systemic autoimmunity. Scientists have found that mice lacking this enzyme had overactive effector T cells as well as suppressive T cells with impaired activity.

Finding ways to treat autoimmune disease without suppressing the basic immune response is a major research goal.

**The NIH budget: great promise - and grave danger**

AAI is very grateful to this subcommittee and the Congress for doubling the NIH budget from FY 1999 to FY 2003 and for addressing the extremely serious problem caused by post-doubling sub-inflationary budget increases through passage of both The American Recovery and Reinvestment Act of 2009 ("ARRA"), which provided \$10.4 billion to NIH, and the FY 2009 Appropriations Act, which provided a 3.2% budget increase (\$938 million) over FY 2008. NIH is now in the extraordinary position of being able to fund many worthy, innovative projects that had been denied funding, to invest in modernizing and enhancing the nation's research infrastructure, and to support needed scientific and administrative jobs that are crucial to the scientific enterprise. This infusion of funds, together with the exceptional commitment to advancing scientific research articulated by President Obama, is also giving our brightest young students the confidence and desire to pursue careers in biomedical research, a crucial factor in helping research advances today become cures tomorrow.

Passage of ARRA served as Congressional acknowledgement of the multi-faceted impact of investing in biomedical research and the NIH: improving individual and global health, and stimulating local and national economic activity and job creation. NIH has estimated that each NIH grant supports on average, "6 to 7 in-part or full scientific jobs."<sup>6</sup> And Families USA, a not-for-profit consumer advocacy organization, has reported that 1) on average, each \$1 of NIH funding going into a state generates more than twice as much in state economic output, and 2) in FY 2007, NIH funding created and supported more than 350,000 jobs that generated wages in excess of \$18 billion, with an average wage of \$52,000 (nearly 25% higher than the average U.S. wage).<sup>7</sup>

While AAI - and the entire biomedical research community - is deeply grateful for ARRA's tremendous influx of funds and support, some of the constraints accompanying the ARRA funding (*i.e.*, that the funds must be obligated by the end of FY 2010 and must be used for immediate economic impact, including creating jobs) are somewhat inconsistent with the longer view and nature of science and the strong need for

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<sup>6</sup> Testimony of Raynard S. Kington, M.D, Ph.D., Acting Director, National Institutes of Health, Witness appearing before the House Subcommittee on Labor-HHS-Education Appropriations Subcommittee, March 26, 2009. Dr. Kington was citing the NIH report: "Estimating the Number of Senior/Key Personnel Engaged in NIH Supported Research," study issued October 2008. Study funded by the NIH Evaluation Set-Aside Program, 07-5002-OD-ORIS-OER, administered by the Evaluation Branch, Division of Evaluation and Systematic Assessment, OPASI, Office of the Director, National Institutes of Health.

<sup>7</sup> "In Your Own Backyard: How NIH Funding Helps Your State's Economy," Families USA, (June 2008). The report cited numerous other economic benefits of NIH funding:

- The amount of new business activity generated ranged from \$8.39 billion in California to \$13 million in Wyoming;
- In 14 states, NIH funding generated over \$1 billion in new business activity;
- In 10 states, each dollar of NIH funding generated at least \$2.26 in economic activity;
- In 6 states, more than 20,000 new jobs were created ;
- In 7 states, average wage per new job exceeded \$55k.



reliable, sustained funding. Although significant advances can be made in two years, few projects can be completed in that time. As such, AAI looks ahead with concern to future years, when advances poised to be made may not come to fruition should ARRA funds end without adequate regular appropriations to cushion the reduction. AAI's appropriations recommendations for FY 2010 (and ultimately for 2011, though not offered here), are premised on that concern and designed to address that future.

**AAI recommends a 7% budget increase for FY 2010**

*AAI urges the subcommittee to increase the NIH budget by 7% in FY 2010.* Such an increase would help ensure that research and jobs supported by ARRA funds are not lost, and that ongoing research would be on track to reach its full potential even after the ARRA funding is spent. A 7% budget increase would also put NIH on the path that most scientists have long sought and urgently need: a path of predictable, sustained funding that stabilizes ongoing research projects and the overall research enterprise.

AAI also strongly supports President Obama's request for an additional \$1.5 billion to specifically address recent developments regarding the emergent H1/N1 (swine) influenza virus. This is an important investment in pandemic preparedness, whether that pandemic proves to be influenza or a future pathogen that cannot yet be predicted.

**Other key issues:**

**Seasonal influenza and pandemics**

Seasonal influenza leads to more than 200,000 hospitalizations and about 36,000 deaths nationwide in an average year. A worldwide influenza pandemic could occur at any time. A pandemic as serious as the one that occurred in 1918 could result in the illness of almost 90 million Americans and the death of more than 2 million, at a projected cost of \$683 billion.<sup>8</sup> While research scientists and public health professionals must, of course, respond to emergent threats (such as the current concern related to the H1/N1 flu virus), AAI believes that the best preparation for a pandemic is to focus on basic research to combat seasonal flu, including building capacity, pursuing new production methods (cell based), and seeking optimized flu vaccines and delivery methods.

**Bioterrorism**

To best protect against bioterrorism, scientists should focus on basic research, including working to understand the immune response, identifying new and potentially modified pathogens, and developing tools (including new and more potent vaccines) to protect against these pathogens.

**The NIH "Common Fund"**

The NIH Reform Act of 2006 established within NIH a "Common Fund" (CF) to support trans-NIH initiatives (including those funded under the "Roadmap for Medical Research"). Although AAI recognizes the value of interdisciplinary research, the existence of the CF should not permit the funding of lesser quality research. Instead, all CF applications should be subject to a transparent and rigorous peer review process like all other funded research grant applications. In addition, AAI recommends that the CF not grow faster than the overall NIH budget.

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<sup>8</sup> A report issued by Trust for America's Health ("Pandemic Flu and the Potential for U.S. Economic Recession") predicts that a severe pandemic flu outbreak could result in the second worst recession in the United States since World War II, resulting in a drop in the U.S. Gross Domestic Product of over 5.5%.

#### **The “NIH Public Access Policy”**

AAI respectfully requests that the subcommittee require that NIH report on the cost of implementing the NIH Public Access Policy (Policy). To the best of AAI’s knowledge, NIH has not reported the cost of the former voluntary Policy or the projected cost of the new mandatory Policy. AAI therefore requests that the subcommittee require NIH to publicly report 1) the total funds expended on implementing the voluntary Policy (May 2, 2005 - January 11, 2008); 2) the cost of implementing the mandatory Policy in FY 2009; and 3) how much of the cost for FY 2009 was a one-time implementation cost, and how much will be an annual cost. AAI further requests that NIH report all costs incurred by the National Library of Medicine (NLM) as well as the various NIH Institutes, Centers, and Offices involved, including: a) the number of FTEs and contracted services used to implement this Policy; b) the cost of personnel and administrative services (including associated space for infrastructure and personnel); c) time spent directly on the promotion, management, enforcement, and assessment of the Policy to/by NIH grantees and the public; and d) all costs associated with network infrastructure improvements including but not limited to bandwidth capabilities, server capacity, and equipment.

AAI continues to believe that the Policy will duplicate, at great cost to NIH and to taxpayers, publications and services which are already provided cost-effectively and well by the private sector. The private sector, including not-for-profit scientific societies, already publishes - and makes publicly available - thousands of scientific journals (and millions of articles) that report cutting-edge research funded by both NIH and other public and private entities. AAI urges that, rather than creating a new government bureaucracy that competes with private publishers, NIH should partner with these publishers to develop a plan that enhances public access while also addressing publishers’ key concerns, which include respecting copyright law and ensuring journals’ continued ability to provide quality, independent peer review of NIH-funded research.

#### **Preserving high quality peer review**

NIH’s recent completion of its “Peer Review Self-Study” has resulted in the adoption and implementation of numerous changes to its internationally respected and highly successful peer review system. While AAI applauds this effort to address some legitimate problems with the system, AAI urges that NIH be required to conduct timely and transparent evaluation of all pilot projects and permanent changes, and provide ample opportunity for public comment.

#### **Ensuring NIH operations and oversight**

AAI urges the subcommittee to ensure adequate funding for the NIH Research, Management, and Services (RM&S) account, which supports the management, monitoring, and oversight of all research activities (including peer review). Particularly with the infusion and rapid dissemination of ARRA funds, NIH must have the ability to ensure proper supervision and oversight of its increasingly large and complex portfolio.

#### **Conclusion**

AAI greatly appreciates this opportunity to submit testimony and thanks the Chairman and members of the subcommittee for their strong support for biomedical research, the NIH, and the scientists who devote their lives to preventing, treating, and curing disease.

**Testimony by Dr. Ford W. Bell, DVM,  
President of the American Association of Museums  
to the House Appropriations Subcommittee on Labor, HHS and Education  
April 28, 2009**

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The American Association of Museums appreciates the opportunity to submit testimony in support of the Institute of Museum and Library Services (IMLS)'s Office of Museum Services (OMS), funded by the Subcommittee on Labor, Health and Human Services and Education.

The American Association of Museums represents the full range of our nation's museums – including aquariums, arboretums, archaeological museums, art museums, botanical gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, nature centers, planetariums, presidential libraries, science and technology centers, zoological parks, and other specialty museums – along with professional staff and volunteers who work for and with museums.

AAM currently represents approximately 17,000 individual museum professionals and volunteers, 3,000 institutions, and 300 corporate partners to museums. Our membership is as diverse as the collections contained in the museums we represent. The Institute of Museum and Library Services (IMLS) is the primary federal agency responsible for supporting the nation's 17,500+ museums, and its Office of Museum Services (OMS) awards grants to all types of museums to support activities ranging from educational programming and professional development to collections management and conservation and preservation efforts.

In this current economic crisis, the demand for museum services is greater than ever. At a time when many families cannot afford to travel and school resources are strained, museums are working overtime to fill the gaps – bringing art and cultural heritage, dynamic exhibitions and living specimens into local communities, providing more than 18 million instructional hours to schoolchildren and offering free or reduced admission. In fact, 35% of museums are always free to the public. More than 98% offer free or reduced admission days, and the average museum admission cost is only \$7.

Yet, like so many other non-profits, museums are struggling significantly in these difficult economic times. They are being forced to cut back on hours, educational programming, community services and jobs. Some are struggling just to keep their doors open, and some have shut down altogether. At a time when many families are re-discovering museums as an affordable family activity, museums are being squeezed by state and local budget cuts, limiting public access to some of our nation's treasured collections.

And according to the 2005 *Heritage Health Index*, at least 190 million artifacts are at risk, suffering from light damage and harmful and insecure storage conditions. OMS grant funding helps to ensure that museums and their collections can continue to play a vital role in the preservation and interpretation of cultural and natural heritage.

**We recommend a significant new investment in our nation's museums to support the important work they are doing in our communities. We respectfully request your approval of \$50 million for grants to museums administered through the Office of Museum Services at the Institute of Museum and Library Services** to support museums as institutions of learning and exploration, and keepers of our cultural, historical, and scientific heritages. OMS grant funding helps museums digitize, enhance and preserve their collections; broaden their reach into schools and communities; provide educators with professional development; and create innovative, diverse, cross-cultural and multi-disciplinary programs and exhibits.

Boston College's Logan Museum of Anthropology in Beloit, Wisconsin, for example, used OMS grant funding to convert more than 50,000 paper-based catalog records to electronic format. Through this project, the museum was able to improve public access to collections, reach a broader audience, increase points of access to collections for educational use, inspire collaborations on and off campus, and facilitate data sharing. The museum houses approximately 15,000 ethnographic and 160,000 archaeological objects from 12 countries and 169 Native American tribes. The museum worked in partnership with researchers and educators to use these collections extensively for object-based learning, contributing to Beloit College's leadership in undergraduate anthropology and museum studies.

Teachers, students, and researchers benefit when cultural institutions, like the Logan Museum, are able to increase access to trustworthy information through online collections and exhibits. Most museums, however, need more help in digitizing collections to meet this need. This is especially important when geographical distance prevents travel to a wide range of museums.

Another recent recipient of OMS grant funding, the Spencer Museum of Art (SMA) at the University of Kansas, is developing a collaborative, art-museum-centered communication model designed to address the multiple learning styles of its visitors. The goals of the initiative are to introduce actual and virtual technologies to connect with new audiences, to collaborate with diverse community participants, to create multiple model teaching and learning styles across disciplines, to use two environment-themed art/science SMA exhibitions for model content areas, to train Kansas University preservice teachers to incorporate these techniques into future curricula, and to develop a multi-format teacher training resource. The project will help develop new relationships and audiences, break down stereotypes about art museums, and create a lasting impact by training teachers to bring the next generation of learners to the museum.

Although the Office of Museum Services has been successful in creating and supporting projects like these, still only a small fraction of the nation's museums are currently being

reached, and many highly rated grant applications go unfunded each year. In 2008, only nine African American History and Culture applications were funded (22.5%). That same year, just 18% of 21st Century Museum Professionals applications and 31.2% of Conservation Project Support applications were funded. Conservation Project Support is especially important as more and more museums struggle to protect and preserve their collections. According to the 2005 *Heritage Health Index*, 59% of museums have collections damaged by light; 56% have insufficient security to protect their collections; 80% do not have an emergency plan that includes collections; 71% need additional training and expertise for staff caring for collections; and only 13% have access to endowment funds for preservation.

Americans view museums as one of the most important resources for educating our children and as one of the most trustworthy sources of objective information. This credibility stems, in part, from the solid foundation collections and research provide for exhibitions and educational programs. Collections – including artifacts and specimens – play a vital role in the preservation and interpretation of cultural and natural heritage and must be safeguarded for current and future generations to sustain a culture of lifelong learning.

Additionally, many museums are located in areas where they are the only cultural resource and where significant private support is simply not available. OMS specifically targets funding for these institutions, providing vital competitive grants. This is important because museums encourage local economic growth, spending more than \$14.5 billion a year in their communities and ranking among the top three family vacation destinations.

In fact, cultural and heritage activities account for more than 23% of all domestic tourism. Both the U.S. Conference of Mayors and the National Governors Association agree that cultural assets such as museums are essential to attracting businesses, a skilled workforce, and local, regional, and international tourism, with the U.S. Conference of Mayors finding, "The arts, humanities, and museums are critical to the quality of life and livability of America's cities."

People of all ages and backgrounds come to learn about the past and present, the natural and cultural world, and human creativity through unique museum experiences. Children find the spark that inspires them to become scientists, artists, political leaders, historians, and entrepreneurs. And because museums are reaching increasingly diverse audiences, they are helping communities better understand and appreciate cultural diversity.

Museums are also key partners in education. The educational role of museums is at the core of their service to the public. They spend more than \$1 billion annually on K-12 educational programming and receive approximately 90 million visits each year from school students. In fact, museums offer educational programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography, and social studies, often in coordination with state and local curriculum

standards. And they reach beyond the scope of instructional programming for schoolchildren by also providing professional development for educators.

At the Detroit Science Center in Michigan, for example, OMS grant funding supported school community outreach activities, including teacher professional development, Traveling Science outreach programs to schools and other community-based organizations. It helped establish curriculum and science activity kits for science classrooms, and after-school science clubs and increased sponsorship of field trips for schools and organizations that serve minority and disadvantaged youth.

It is clear that through museums, visitors make tangible connections to their heritage, art, or the natural world regardless of their ages, the size of their communities, or their economic and ethnic backgrounds.

We urge the Subcommittee to fund the Office of Museum Services at IMLS at \$50 million for FY10 so that museums can continue to carry out their public service, educational, and conservation roles in connecting the whole of society to the cultural, historical, and scientific understanding that constitute our heritage.



Written Statement of

**Jackie Rowles , CRNA, MBA, MA, FAAPM  
President**

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**House Appropriations Subcommittee  
On Labor, Health and Human Services, and Education**

2358-C Rayburn Building  
Washington, DC  
May 1, 2009

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**FY 2010 Appropriations Request Summary**

	<u><b>FY09 Actual</b></u>	<u><b>FY10 Budget</b></u>	<u><b>AANA FY 10 Request</b></u>
HHS / HRSA / BHP Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve	Awaiting grant allocations—in FY08 awards amounted to approx. \$3.5MM	Grant allocations not specified	\$4 MM for nurse anesthesia education
Total for Advanced Education Nursing, from Title VIII	\$64.44 for Advanced Education Nursing	Grant allocations not specified	\$79.55 MM for advanced education nursing
Title VIII HRSA BHP Nursing Education Programs	\$171,031,000	Not specified	\$215,000,000

The AANA is the professional association for more than 40,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs are directly involved in delivering 30 million anesthetics given to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases, and in some states are the sole anesthesia providers in almost 100

percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety in the field of anesthesia was bolstered by the Institute of Medicine report in 2000, which found that anesthesia is 50 times safer than 20 years previous. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Nurse anesthetists continue to set for themselves the most rigorous continuing education and re-certification requirements in the field of anesthesia. Relative anesthesia patient safety outcomes are comparable among nurse anesthetists and anesthesiologists, with Pine having concluded, "the type of anesthesia provider does not affect inpatient surgical mortality." (Pine, Michael MD et al. "Surgical mortality and type of anesthesia provider." *Journal of American Association of Nurse Anesthetists*. Vol. 71, No. 2, p. 109 – 116. April 2003.)

Even more recently, a study published in *Nursing Research* indicates that obstetrical anesthesia, whether provided by Certified Registered Nurse Anesthetists (CRNAs) or anesthesiologists, is extremely safe, and there is no difference in safety between hospitals that use only CRNAs compared with those that use only anesthesiologists. (Simonson, Daniel C et al. "Anesthesia Staffing and Anesthetic Complications During Cesarean Delivery: A Retrospective Analysis." *Nursing Research*, Vol. 56, No. 1, pp. 9-17. January/February 2007). In addition, a recent AANA workforce study showed that CRNAs and anesthesiologists are substitutes in the production of surgeries, and it is important to note that through continual improvements in research, education, and practice, nurse anesthetists are vigilant in their efforts to ensure patient safety.

CRNAs provide the lion's share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves. In May 2003 at the beginning of "Operation Iraqi Freedom," 364 CRNAs were deployed to the Middle East to ensure military medical readiness capabilities. For decades, CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas and areas where more Medicare patients live. A recent analysis of the nurse anesthesia workforce indicates that in 2006, 38% of nurse anesthesia graduates went to work in a Medically Underserved Area or for a Medically Underserved Population.

### **Importance of Title VIII Nurse Anesthesia Education Funding**

The nurse anesthesia profession's chief request of the Subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$79.55 million for advanced education nursing from the Title VIII program. We feel that this funding request is well justified, as we are seeing a vacancy rate of nurse anesthetists in the United States that is impacting the public's access to healthcare. The Title VIII program, which has been strongly supported by members of this Subcommittee in the past, is an effective means to help address the nurse anesthesia workforce demand. This demand for CRNAs is something that the nurse anesthesia profession addresses



every day with success and also with the critical assistance of federal funding through HHS' Title VIII appropriation.

Increasing funding for advanced education nursing from \$64.44 million to \$79.55 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the United States. Only a limited number of new programs and traineeships can be funded each year at the current funding levels. The program provides for competitive grants that help enhance advanced nursing education and practice and traineeships for individuals in advanced nursing education programs. This funding is critical to meet the nursing workforce needs of Americans who require healthcare. In fact, this funding not only seeks to increase the number of providers in rural and underserved America but also prepares providers at the master's and doctoral levels, increasing the number of clinicians who are eligible to serve as faculty.

The CRNA workforce is seeing a shortage in the clinical and educational setting. In 2007, the AANA conducted a nurse anesthesia workforce study that found a 12.6% vacancy rate in hospitals for CRNAs, and a 12.5% faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. Between 2000-2008, the number of nurse anesthesia educational program graduates doubled, with the Council on Certification of Nurse Anesthetists (CCNA) reporting 1,075 graduates in 2000 and 2,158 graduates in 2008. This growth is expected to continue. However, it is important to note that even though the number of graduates has doubled in eight years, the nurse anesthetist vacancy rate remained steady at around 12%, which is likely due to increased demand for anesthesia services as the population ages, growth in the number of clinical sites requiring anesthesia services, and CRNA retirements.

The problem is not that our 108 accredited programs of nurse anesthesia are failing to attract qualified applicants. It is that they have to turn them away by the hundreds. The capacity of nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least one year serving in an acute care healthcare practice environment. Nurse anesthesia educational programs are located all across the country including the following states:

<i>State</i>	<i># of Accredited Nurse Anesthesia Programs</i>
AL	2
CA	3
CT	3
IL	5
KS	2
LA	2
MN	4
NY	4
OH	5
RI	2
VA	2

Recognizing the important role nurse anesthetists play in providing quality healthcare, the AANA has been working with the 108 accredited nurse anesthesia educational programs to increase the number of qualified graduates. In addition, the AANA has worked with nursing and allied health deans to develop new CRNA programs.

To truly meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow. With the help of competitively awarded grants supported by Title VIII funding, the nurse anesthesia profession is making significant progress, expanding both the number of clinical practice sites and the number of graduates.

The AANA is pleased to report that this progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. As mentioned earlier, the study by Pine et al confirms, "the type of anesthesia provider does not affect inpatient surgical mortality." Yet, for what it costs to educate one anesthesiologist, several CRNAs may be educated to provide the same service with the same optimum level of safety. Nurse anesthesia education represents a significant educational cost-benefit for supporting CRNA educational programs with federal dollars vs. supporting other, more costly, models of anesthesia education.

To further demonstrate the effectiveness of the Title VIII investment in nurse anesthesia education, the AANA surveyed its CRNA program directors in 2003 to gauge the impact of the Title VIII funding. Of the eleven schools that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding from 1998 to 2003, the programs indicated an average increase of at least 15 CRNAs graduated per year. They also reported on average more than doubling their number of graduates who provide care to patients during and following their education. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas.

We believe it is important for the Subcommittee to allocate \$4 million for nurse anesthesia education for several reasons. First, as this testimony has documented, the funding is cost-effective and needed. Second, the Title VIII authorization previously providing such a reserve expired in September 2002. Third, this particular funding is important because nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. Lastly, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

### **Title VIII Funding for Strengthening the Nursing Workforce**

The AANA joins a growing coalition of nursing organizations, including the Americans for Nursing Shortage Relief (ANSR) Alliance and representatives of the nursing community, and others in support of the Subcommittee providing a total of \$215 million in FY 2010 for nursing shortage relief through Title VIII. This amount is approximately \$44 million over FY 2009.

Every district in America is familiar with the importance of nursing. The AANA appreciates the support for nurse education funding in FY 2009 and past fiscal years from this Subcommittee and from the Congress.

The need for increasing nurse educational funding to strengthen our health care is clear. According to the Office of the Actuary at the Centers for Medicare & Medicaid Services, America spent about \$2.17 trillion on healthcare in 2006, which is the most recent year for which the agency had records. About \$401 billion of that was from Medicare outlays. Medicaid spending was \$309 billion. It is estimated that Medicare directs approximately \$8.4 billion of its outlays to Graduate Medical Education (GME), of which about \$2.3 billion goes to Direct GME. Approximately 99 percent of that educational funding helps to educate physicians and allied health professionals, and about 1 percent is allocated to help educate nurses.

In the interest of patients past and present, particularly those in rural and medically underserved parts of this country, we ask Congress to invest in CRNA and nursing educational funding programs and to provide these programs the sustained increases required to help ensure Americans get the healthcare that they need and deserve. Quality anesthesia care provided by CRNAs saves lives, promotes quality of life, and makes fiscal sense. This federal support for nurse education will improve patient access to quality services and strengthen the nation's healthcare delivery system.

### Safe Injection Practices

Last, as a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Safe Injection Practices Coalition, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections, an issue on which the Subcommittee recently hosted a hearing. We associate ourselves with the funding requests presented by HonoReform, and by Reps. Shelley Berkley, Ed Towns, Jeff Fortenberry, Dina Titus, Lee Terry and Andre Carson in their FY 2010 request to you. In the interest of promoting safe injection practice, and reducing the incidence of healthcare facility acquired infections, we recommend the Committee provide the following appropriations for FY 2010:

- *Centers for Disease Control and Prevention:* \$9 million for provider education and patient awareness activities; \$8 million to promote private-sector healthcare solutions to injection safety and infection control problems; \$9 million for detection and tracking in order to enable states to investigate outbreaks of hepatitis and other potential pathogens related to injection safety.
- *Agency for Healthcare Research and Quality (AHRQ):* \$10 million in general patient safety funds for the Agency for Healthcare Research and Quality's Ambulatory Patient Safety Program.
- *Department of Health and Human Services (HHS):* \$1 million to expand its current focus for reducing HAIs from hospitals to all healthcare settings, including outpatient facilities.

Thank you.

# # #

**Written Testimony on behalf of  
The American Brain Coalition  
Submitted By Joseph T. Coyle, M.D., Chair  
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**Submitted to the United States House of Representatives  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**

**Fiscal Year 2010  
Appropriations for the Department of Health and Human Services  
May 1, 2009**

**Introduction**

The National Institutes of Health (NIH) is the world's leader in medical discoveries that improve people's health and save lives. NIH-funded scientists at universities and research centers throughout the nation investigate ways to prevent, treat, and even cure the complex diseases of the brain. Because there is much work still to be done, the American Brain Coalition writes to ask for the House Appropriations Committee's continued support for increased biomedical research funding at NIH.

**What is the American Brain Coalition?**

The American Brain Coalition (ABC) is a nonprofit organization that seeks to reduce the burden of brain disorders and advance the understanding of the functions of the brain. The ABC, made up of nearly 50 member organizations, brings together afflicted patients, the families of those that suffer, the caregivers, and the professionals that research and treat diseases of the brain.

The brain is the center of human existence, and the most complex living structure known. As such, there are thousands of brain diseases from Rett Syndrome and autism to mental illness and Parkinson's disease. The American Brain Coalition, unlike any other organization, brings together people affected by *all* diseases of the brain.

The ABC is working to raise public awareness and support for diseases of the brain. Fifty million Americans – our relatives, friends, neighbors, and your constituents – are affected by diseases of the brain. This number does not include the millions more family members whose lives are affected as they care for those who suffer. Our goal is to be a united voice for these patients, and to work with Congress and the Administration to alleviate the burden of brain disease. A large part of that goal involves support for NIH research.

**Thank You for Your Support**

The American Brain Coalition would like to thank the Members of this Subcommittee and the House for its support for the \$10 billion for the National Institutes of Health in the recent economic stimulus package. This funding will provide the opportunity for a substantial number of two year research grants and infrastructure project to move forward and enhance our understanding of an array of physical and mental health concerns.

The generous funding in the economic stimulus package is crucial to advancing science because NIH has been relatively flat funded since its budget doubling was completed in 2003. Some policymakers feel the agency had all it needed once the budget was doubled. Yet, these subsequent smaller budget increases, over time, have essentially undone the results of the budget-doubling achieved 6 years ago. Currently, less than ten percent of submitted grants are funded, and much worthy research has languished. Therefore, the infusion of \$10 billion is much-needed, as is a further budgetary increase in FY 2010, particularly if NIH is to attain President Obama's goal of another budget-doubling over ten years.

**NIH-Funded Research Successes**

Today, scientists have a greater understanding of how the brain functions due to NIH-funded research. These research efforts have improved the health of the American public.

**Parkinson's Disease (PD)** occurs when nerve cells become damaged or destroyed in a part of the brain that is important for normal voluntary movement and coordination. This results in trembling, muscle stiffness, and slowness of movement. Other difficulties resulting from PD are depression, anxiety, dementia, constipation, urinary difficulties, and sleep disturbances. Unfortunately, these symptoms only worsen over time. PD affects 1 million people currently, with an average of 50,000 Americans being diagnosed each year. Men are 1.5 to 2 times more likely to be affected by Parkinson's Disease than women. The societal cost of Parkinson's Disease—visits to doctors, Social Security payments, nursing home expenditures, and lost income—is estimated at \$5.6 billion annually. Additionally, medication for PD patients averages \$4,000 a year.

Past NIH-funded research has led to the discovery of drugs called dopamine agonists that cause fewer side effects and last for longer periods of time than the earlier drug levodopa (L-dopa), which reduced tremors and other symptoms of PD. Thanks to the responsible use of animal models, scientists pinpointed the structures within the brain that contribute to Parkinson's symptoms, thereby making them targets for therapeutic intervention. Because of basic neurophysiologic research carried out in the 1990s, scientists have now found that deep brain stimulation of the thalamus suppressed tremors in patients. Deep brain stimulation involves an electrode, which is surgically implanted into the brain, being connected to a pulse generator implanted under the skin that can be adjusted to control the disabling shaking caused by PD. Deep brain stimulation now holds promise for the treatment of an expanding number of disorders including Tourette syndrome, dystonia and depression, demonstrating the commonality of brain disorders at a fundamental level.

Further NIH-funded research could lead to the discovery of a biomarker—a biochemical abnormality that all patients with Parkinson's might share—that could be detected by a simple chemical test or other screening technique before symptoms develop. Scientists are getting closer to understanding the relationship between environmental toxins, mitochondria (the part of cells that produce energy) and Parkinson's. However, more could be discovered about whether antioxidants—substances that repair damaged cells—might slow the progression of PD, or whether it is possible to replace damaged dopamine brain cells with stem cells. Scientists are also finding that PD has much in common with other neurodegenerative disorders. Therefore, progress made in Parkinson's research could also hold promise for Alzheimer's disease, amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease) and Huntington's disease.

**Schizophrenia** is a devastating brain disorder whereby patients suffer from hallucinations, delusions, disordered thinking patterns, impaired social interactions and memory deficits. It strikes in the teen years and 20s, leading to life-long disability. The societal cost of schizophrenia is estimated at \$32.5 billion a year. Sadly, many schizophrenics become lost to the behavioral and social problems associated with this disease, resulting in chronic homelessness.

The fruits of the Human Genome Project are being brought to bear on schizophrenia and related severe mental disorders. In the last few years, a number of genes that contribute to the risk of schizophrenia have been identified. Scientists have generated mice in which these “risk genes” have been inserted in their chromosomes and are identifying how they disrupt brain function and behavior. Similar strategies are being explored for other serious mental disorders including bipolar disorder, autism, fragile x syndrome and depression. These fundamental insights hold the promise of identifying molecular targets for more effective treatments.

Clearly, federal investment in research has led to significant improvements in diagnoses and patient care for a variety of brain diseases and disorders.

#### **Research Improves Health and Fuels the Economy**

Diseases of the nervous system pose a significant public health and economic challenge, affecting nearly one in three Americans at some point in life. Improved health outcomes and positive economic data support the assertion that biomedical research is needed today to improve public health and save money tomorrow.

Not only does research save lives and fuel today’s economy, it is also a wise investment in the future. For example, 5 million Americans suffer from Alzheimer’s disease today, and the cost of caring for these people is staggering. Medicare expenditures are \$91 billion each year, and the cost to American businesses exceeds \$60 billion annually, including lost productivity of employees who are caregivers. As the baby boom generation ages and the cost of medical services increases, these figures will only grow. Treatments that could delay the onset and progression of the disease by even five years could save \$50 billion in healthcare costs each year. Research funded by the NIH is critical for the development of such treatments. The cost of investing in NIH today is minor compared to both current and future healthcare costs.

Additionally, it is estimated that each billion of dollars of NIH funding generates 15,000 to 20,000 jobs. Science funding also generates more than twice as much in state and local economic output. A strong federal investment in research can assist your state in maintaining a biomedical research foundation that attracts companies and investors. For instance, in FY2007, NIH dollars generated more than \$50 billion in new state business. Strong science funding can bolster the economy today and improve our nation’s long term health and competitiveness tomorrow.

#### **FY 2010 Recommendation**

The American Brain Coalition supports an increase in funding for the National Institutes of Health in FY 2010 of 10%, excluding the one time stimulus allocation.

Sustaining this increase over a period of years is necessary to begin to make up for the 13 percent lost purchasing power that has occurred in the past six years. In addition, it will help the NIH to achieve its broad research goals and provide hope for the millions of Americans affected with neurological and psychiatric disorders.

There is still much work to be done to uncover the mysteries of the brain. The recent start-stop funding approach has made efficient research planning extremely difficult, disrupted the continuity of research programs, has stalled progress, and must be reversed. To not do so

threatens scientific progress, economic advancement, and the health of the American people. A new fiscal year provides a fresh start to make health funding a top priority again for Congress.

Mr. Chairman, thank you for the opportunity to submit testimony before this Subcommittee.



Testimony Submitted by the  
American College of Obstetricians and Gynecologists

US House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services and Education

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May 1st, 2009

The American College of Obstetricians and Gynecologists (ACOG), representing 53,000 physicians and partners in women's health care, is pleased to offer this statement to the House Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Obey, Ranking Member Tiahrt, and the entire Subcommittee for their leadership to continually address women's health. Our goal is to ensure continued support of the many Department of Health and Human Services (HHS) programs which support research into women's health issues.

The American Recovery and Reinvestment Act (ARRA) made a sizeable down payment on health care programs that have been underfunded in recent years. The \$10.4 billion for the National Institutes of Health (NIH) and the commitment to comparative effectiveness research will help to foster innovation and convey best practices to physicians. While ACOG is thankful for the generous funding from the stimulus package, funds for NIH must be used within two years, limiting the ability of programs to be carried out to their completion.

An increase in funds through the regular appropriations process will help supplement programs supported by the stimulus package beyond the two-year mark. Therefore, we urge the Committee to support an appropriation of at least \$32.4 billion for NIH, a \$2.1 billion increase (7%) for FY 2010. ACOG supports a \$90.6 million increase (7%) in funds over FY 2009 for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) at NIH. We also continue to support efforts to secure adequate funds for important public health programs at the Health Resources and Services Administration (HRSA), \$8.5 billion, and the Centers for Disease Control and Prevention (CDC), \$8.6 billion, (including funding for the Agency for Toxic Substances and Disease Registry) for CDC's core programs, excluding the mandatory funding provided for the Vaccines for Children Program (VFC).

**I. Ensuring Medically Accurate Education and Preventing Teen Pregnancies**

**Comprehensive Sexuality Education and Teen Pregnancy Prevention**

Young people need education that encourages them to delay sexual activity while providing them with accurate information about how to protect themselves against unintended pregnancies and sexually transmitted infections (STIs). The National Center for Health Statistics (NCHS) found that the teen birth rate in the United States has risen two years in a row with a three

percent increase between 2005 and 2006-the first such increase in 15 years- and a 1.4 percent increase between 2006 and 2007. More than 750,000 teenagers become pregnant each year, and 80% of these pregnancies are unintended. A March 2008 CDC report found that 25% of girls and young women ages 14 to 19 have at least one of four common STIs. These statistics show that abstinence-only programs alone are not effective in preventing sexual activity among teenagers.

Since 1996, Congress has committed over half a billion dollars in federal and state funding for abstinence-only education programs. In order to qualify for federal funding, some of these programs are prohibited from discussing medically accurate information about contraceptives and STIs. While it is valuable to promote abstinence from sexual intercourse as the preferred responsible behavior for adolescents, reputable studies show that comprehensive programs that provide scientifically accurate information about sexuality, STIs, contraception, preventive health care, and abstinence, are the most effective in combating teen pregnancy and STIs.

ACOG urges Congress to defund abstinence-only programs and to provide funds for comprehensive sexual education programs.

## **II. Improving Contraceptive Research and Access to Family Planning**

### **Contraceptive Research**

**Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**

The United States has one of the highest unintended pregnancy rates of the industrialized nations. Of the approximately 6 million pregnancies each year, an estimated one half is unintended. Contraceptive use saves as much as \$19 billion in health care costs annually. Research has found that oral contraceptives are less effective in overweight and obese women, yet the causes are unknown. It is critical that Congress continue to invest in contraceptive research, ensuring that women have access to safe and effective contraceptives to help them time and space their pregnancies. The NICHD's research on male and female contraceptives can help reduce the number of unintended pregnancies and abortions, and improve women's health.

### **Title X Family Planning Program**

**Health Resources and Services Administration (HRSA)**

Since 1970, the Title X Family Planning program at HRSA has provided low-income women with timely screenings, education, and contraception, services that can help prevent breast and cervical cancer, sexually transmitted infections (STIs), and unintended pregnancies.

Title X clinics serve more than five million low-income women at 4,500 clinics nationwide, helping women plan the number and timing of their pregnancies and stay healthy. One in seven women gets her Pap test, and one in three women get tested or treated for STIs at family planning clinics. Title X clinics are serving increasing numbers of patients without commensurate increases in funding. We urge you to increase funding for this vital program to \$700 million.

## **III. Ensuring All Women Have Safe and Healthy Pregnancies**

**Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**

**Drug Safety During Pregnancy**

In 2004, NICHD created the Obstetric and Pediatric Pharmacology Branch to centralize research on the effect of prescription drugs on children and pregnant women.

Obstetricians and their pregnant patients need much more information on the fetal and maternal risks and benefits of medications. ACOG urges Congress to support the Branch's research on the interactions between therapeutics, pregnancy and development, and training in reproductive, perinatal, and pediatric epidemiology.

**Reducing High-Risk Pregnancies**

NICHD's Maternal Fetal Medicine Unit Network, working at 14 sites across the U.S. will help reduce the risks of cerebral palsy, caesarean deliveries, and gestational diabetes. ACOG urges Congress to increase funding for this Network and its important research.

NICHD's MFM Unit Network sites include: University of Alabama, University of Texas-Houston, University of Texas-Southwestern, Wake Forest University, University of North Carolina, Brown University-Women and Infant's Hospital, Columbia University, Drexel University, University of Pittsburgh-Magee Women's Hospital, University of Utah, Northwestern University, Wayne State University, Case Western University, and Ohio State University.

**Reducing the Prevalence of Premature Births**

NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial groups, and how to reduce these risks. Prematurity rates have increased almost 35% since 1981, accounting for 12.5% of all births, yet the causes are unknown in 25% of cases. The 2008 Surgeon General's Conference on the prevention of preterm birth brought together experts from the public and private sectors to discuss key research findings and to develop an agenda to mitigate the problem of prematurity. The conference concluded by calling on the surgeon general to make the prevention of preterm birth a national public health priority. ACOG supports this effort and urges Congress to recognize the importance of new research to identify the causes and effective interventions for preterm births.

**IV. Improving Maternal and Infant Health**

**Healthy Start Program**

**Health Resources and Services Administration (HRSA)**

After decades of decline, the U.S. infant mortality rate is again on the rise and is particularly severe among minority and low-income women. The infant mortality rate among African American women has been increasing since 2001 and reached 14.2 deaths per 1,000 births in

2004. There also has been a startling rise in infant mortality in the South. Mississippi, for example, had an infant mortality rate of 11.4 in 2005 compared to 9.6 the previous year.

The Healthy Start Program through HRSA promotes community-based programs that focus on infant mortality and racial disparities in perinatal outcomes. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to help solve problems related to infant mortality. Today more than 220 local programs in 42 states find FIMR a powerful tool to help solve infant mortality.

ACOG urges you to fund the Healthy Start program at \$120 million in FY10 to help lower the high infant mortality rate, and address issues related to disparities.

**Pregnancy Risk Assessment Monitoring System  
Centers for Disease Control and Prevention (CDC)**

The Pregnancy Risk Assessment Monitoring System (PRAMS), a joint project of the CDC and state health departments, collects state-specific data on maternal attitudes and experiences before, during, and shortly after pregnancy. PRAMS data helps identify women and infants at high risk for health problems and monitor changes in health status. Despite its success, federal funding limits mean the CDC can only operate PRAMS programs in 38 states. ACOG urges Congress to fund PRAMS in all 50 states.

**National Center on Birth Defects and Developmental Disabilities (NCBDDD)  
Centers for Disease Control and Prevention (CDC)**

Birth defects affect about one in every 33 babies born in the United States each year. Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects. Preventing birth defects should be a national priority.

The NCBDDD and ACOG have worked together on a number of proven prevention efforts, including increasing understanding of genetic screening and diagnostic tests, technical guidance on preconception care and prenatal genetic screening, better information on ways to reduce maternal alcohol use, better care for women with gestational diabetes mellitus and improved access to care for women with disabilities. ACOG urges Congress to increase funding for the NCBDDD.

**V. Issues Throughout A Woman's Lifespan: Breast and Cervical Cancer**

**Vaccines for Children (VFC) and the Section 317 Program  
Centers for Disease Control and Prevention (CDC)**

A new vaccine can protect girls and women from cervical cancer. In 2006, the Food and Drug Administration (FDA) approved the vaccine Gardasil for girls and women ages 9-26 to prevent certain types of human papilloma virus (HPV) which can lead to cervical cancer.

The VFC and the Section 317 programs at the CDC provide vaccines for children and low-income adults, but at \$350 for the three dose regimen, many families cannot afford the vaccine and federal funding leaves these programs badly underfunded. Congress should increase funding for the VFC and the Section 317 programs in FY10 to ensure the availability of the HPV vaccine to these important populations.

The vaccine is an important tool to combat cervical cancer, but it is not a substitute for routine screening. Regular pap tests are necessary to diagnose HPV before it develops into cervical cancer.

**National Breast and Cervical Cancer Early Detection Program  
Centers for Disease Control and Prevention (CDC)**

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides critical breast and cervical cancer screening to low-income, uninsured and underserved women who do not otherwise have access to these lifesaving interventions. Since 1991, the NBCCEDP has conducted over 7.8 million breast and cervical screenings. Yet the program only serves 15% of the eligible population, and the number of women screened for both breast and cervical cancers has decreased each year since 2005. In April 2007, Congress reauthorized this important program, and Congress should ensure the program is funded at its authorized level of \$225 million in FY10 so that it can serve more women in need of the program.

**Medicaid Breast and Cervical Cancer Prevention and Treatment Act (BCCPT)  
Center for Medicare and Medicaid Services (CMS)**

Low-income, uninsured and underinsured women who are found to have breast or cervical cancer after being screened through the NBCCEDP need serious medical care. In 2000, Congress created the Medicaid Breast and Cervical Cancer Prevention and Treatment program to provide this care to 34,535 women to date. This program is also historically underfunded, leaving many women without access to needed care. Congress should fully fund this program, providing states with enough funds to treat women with breast and cervical cancers.

Again, we would like to thank the Committee for its continued support of programs to improve women's health.

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**Statement for the Record of the  
American College of Physicians  
to the House Appropriations Subcommittee on Labor,  
Health and Human Services, Education, and Related Agencies**

**March 19, 2009**

**Re: FY 2010 Budget, Department of Health and Human Services**

Chairman Obey and Ranking Member Tiahrt, thank you for allowing me to share the American College of Physicians (ACP's) views on the Department of Health and Human Services budget for FY 2010.

I am Jeffrey P. Harris, MD, FACP, President of the American College of Physicians, a general internist for three decades, who worked as a Clinical Associate Professor of Medicine at the University of Virginia School of Medicine. Until very recently, I practiced in a small, rural town in Virginia with a population of 40,000 people. I am pleased to be able to represent the College.

The American College of Physicians represents 126,000 internal medicine physicians, residents, and medical students. ACP is also the nation's largest medical specialty society and its second largest physician membership organization.

Today, I am urging the following funding levels:

- Title VII and Title VIII programs, under the Public Health Service Act, \$550 million;
- National Health Service Corps, \$235 million;
- Agency for Healthcare Research and Quality, \$405 million; and
- National Institutes of Health, at minimum a 7% increase over the FY 2009 baseline.

**Primary Care Workforce**

We are experiencing a primary care shortage in this country, the likes of which we have not seen. The expected demand for primary care in the United States continues to grow exponentially while the nation's supply of primary care physicians dwindles and interest by U.S. medical graduates in primary care specialties steadily declines. The reasons behind this decline in primary care physician supply are multi-faceted and complex. Key factors include the rapid rise in medical education debt, decreased income potential for primary care physicians, failed payment policies, and increased burdens associated with the practice of primary care.

A strong primary care infrastructure is an essential part of any high-functioning healthcare system. In this country, primary care physicians provide 52 percent of all ambulatory care visits,

80 percent of patient visits for hypertension, and 69 percent of visits for both chronic obstructive pulmonary disease and diabetes, yet they comprise only one-third of the U.S. physician workforce. Those numbers are compelling, considering the fact that primary care is known to improve health outcomes, increase quality, and reduce healthcare costs.

There are many regions of the country that are currently experiencing shortages in primary care physicians. The Institute of Medicine (IOM) reports that it would take 16,261 additional primary care physicians to meet the need in currently underserved areas alone. To help alleviate the shortage of primary care physicians, we believe sufficient funding should be provided for Title VII and Title VIII programs, as well as the National Health Service Corps.

#### **Title VII and Title VIII Programs**

The health professions education programs, authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration, support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces. The College was pleased that the American Recovery and Reinvestment Act (P.L. 111-5) provided a down payment of \$200 million for Title VII and Title VIII programs.

The College, along with the Health Professions and Nursing Education Coalition, is recommending that these programs require at least \$550 million to adequately educate and train a health care workforce that meets the public's health care needs. This amount includes restoration of Title VII to at least the FY 2005 level (close to \$300 million).

Lower funding or elimination of Title VII programs will have an immediate impact on the training and recruitment of health professions students and the educational infrastructures developed and supported by Title VII. It is important to note that these programs are unique in that they are the only federal investment in interdisciplinary training, which is vitally important as care is often provided in interdisciplinary settings. These programs are also designed to enhance minority representation in the health care workforce, which is essential when it comes to providing access to care as minority providers are more likely than others to care for underserved populations and help reduce the shortages in these specific areas. Moreover, not only does this funding support essential training programs, it also facilitates the delivery of care to the underserved areas of the country through the Area Health Education Centers (AHECs) and Health Education and Training Centers.

As the nation's health care delivery system undergoes rapid and dramatic changes, an appropriate supply and distribution of health professionals has never been more essential to the public's health. The Title VII and Title VIII programs are critical to help institutions and programs respond to these current and emerging challenges and ensure that all Americans have access to appropriate and timely health services.

#### **National Health Service Corps**

In conjunction with other stakeholders, the College is recommending a combined appropriation of \$235 million for the National Health Service Corps (NHSC). We are pleased the ARRA

provided an additional \$300 million, which will enable 4,200 more clinicians to access the scholarship and loan repayment programs.

The NHSC scholarship and loan repayment programs provide payment toward tuition/fees or student loans in exchange for service in an underserved area. The programs are available for primary medical, oral, dental, and mental and behavioral professionals. Participation in the NHSC for four years or more greatly increases the likelihood that a physician will continue to work in an underserved area after leaving the program. Over the years, the number of clinicians in those programs has grown from 180 to over 4,000. In 2000, the NHSC conducted a large study of NHSC clinicians who had completed their service obligation up to 15 years before and found that 52 percent of those clinicians continued to serve the underserved in their practice. The programs under NHSC have proven to make an impact in meeting the health care needs of the underserved, and with more appropriations, they can do more.

The NHSC estimates that nearly 50 million Americans currently live in health professions shortage areas (HPSAs) - underserved communities which lack adequate access to primary care services - and that 27,000 primary care professionals are needed to adequately serve the people living in HPSAs. Currently, over 4,000 NHSC clinicians are caring for nearly 4 million people. The outstanding need remains unmet.

Limited funding has reduced new NHSC awards from 1,570 in FY 2003 to an estimated 947 in FY 2008, a nearly 40 percent decrease. The NHSC scholarship program already receives seven to fifteen applicants for every award available. The National Advisory Council on the National Health Service Corps has recommended that Congress double the appropriations for the NHSC to more than double its field strength to 10,000 primary care clinicians in underserved areas.

#### **Agency for Healthcare Research and Quality**

The Agency for Healthcare Research and Quality (AHRQ) is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, providers, health plans, purchasers, and policymakers to make informed health care decisions.

The College is dedicated to ensuring AHRQ's vital role in improving the quality of our nation's health and supports a fiscal year 2010 budget allocation of \$405 million for AHRQ. This amount will allow AHRQ to carry out its congressional mandate to improve health care quality and reduce costs by identifying which treatments work best and at what cost. The College's request of an additional \$32 million over the FY 2009 funding level would be designated for increased research in patient safety, health information technology, resources for research into the causes of and solutions to raising health care costs, chronic care management and strategies to translate research into practice.

The additional \$32 million will allow AHRQ to expand its investigator-initiated research program, a critically important element of our nation's health care research effort. This funding stream provides for many clinical innovations, innovations that improve patient outcomes. It will also facilitate the translation of research into clinical practice and disease management strategies, and address the health care needs of vulnerable populations. Investment in AHRQ's



investigator-initiated research is an investment in America's health. Additionally, investment in investigator-initiated research represents a cost-effective and efficient use of our federal health research dollars. The relatively modest investment provided to clinical investigators in the form of grants often result in advancements with positive economic implications far outweighing the original investment.

The College was pleased that the ARRA provided AHRQ with \$300 million for comparative clinical effectiveness research. This funding, along with an additional \$400 million for the Office of the Director of the National Institutes of Health and \$400 million to the Secretary of Health and Human Services, will stimulate the development of comparative effectiveness research and provide a good foundation for the establishment of the recommended, national comparative effectiveness entity. Furthermore, the Act prohibits the government from using the research for making any coverage or payment decisions or issuing clinical guidelines. The sole purpose is to develop this research and disseminate the results to all stakeholders.

#### **National Institutes of Health**

Together, the FY 2009 omnibus and the ARRA provided \$38.5 billion to the National Institutes of Health (NIH), which will fund over 16,000 new research grants for life-saving research into diseases such as cancer, diabetes and Alzheimer's.

In his budget, the President envisions doubling our investment in basic research. Consistent with his proposal, we respectfully urge the Subcommittee to increase funding for NIH by at least 7 percent over the FY 2009 baseline.

#### **Conclusion**

Mr. Chairman and Ranking Member Tiahrt, I appreciate the opportunity to offer testimony on the importance of the Department of Health and Human Services budget for FY 2010.

In conclusion, I would like to reiterate the College's recommended funding levels:

- Title VII and Title VIII programs, under the Public Health Service Act, \$550 million;
- National Health Service Corps, \$235 million;
- Agency for Healthcare Research and Quality, \$405 million; and
- National Institutes of Health, at minimum a 7% increase over the FY 2009 baseline.

The United States must invest in these programs in order to achieve a high performance health care system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as you being to work on the FY 2010 appropriations process.

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**Statement of the  
AMERICAN COLLEGE OF PREVENTIVE MEDICINE**

**submitted to the  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED  
AGENCIES SUBCOMMITTEE**

**COMMITTEE ON APPROPRIATIONS  
UNITED STATES HOUSE OF REPRESENTATIVES**

**for the record on  
FISCAL YEAR 2010 APPROPRIATIONS**

**APRIL 9, 2009**

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## RECOMMENDATION

The American College of Preventive Medicine (ACPM) urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing **\$10.1 million in FY 2010 for preventive medicine residency training under the public health, dentistry, and preventive medicine line item in Title VII of the Public Health Service Act.** ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition that \$550 million be appropriated in FY 2010 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

## THE NEED FOR PREVENTIVE MEDICINE IS GROWING

In today's healthcare environment, the tools and expertise provided by preventive medicine physicians are integral to the effective functioning of our nation's public health system. These tools and skills include the ability to deliver evidence-based clinical preventive services, expertise in population-based health sciences, and knowledge of the social and behavioral aspects of health and disease. These are the tools employed by preventive medicine physicians who practice in public health agencies and in other healthcare settings where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.<sup>1, 2, 3</sup>

Organizations across the spectrum have recognized the growing demand for public health and preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year"<sup>15</sup>. The Health Resources and Services Administration's (HRSA) Bureau of Health Professions, using data extracted from the Department of Labor, reports that the demand for public health professionals will grow at twice the rate of all occupations between 2000 and 2010.<sup>4</sup> The Council on Graduate Medical Education recommends increased funding for training physicians in preventive medicine.<sup>5</sup> In addition, the nation's medical schools are devoting more time and effort to population health topics.<sup>6</sup> These are just a few of the examples demonstrating the growing demand for preventive medicine professionals.

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties *that requires and provides training in both clinical medicine and public health*. Preventive medicine physicians possess critical knowledge in population and community health issues, disease and injury prevention, disease surveillance and outbreak investigation, and public health research. Preventive medicine physicians are employed in hospitals, state and local health departments, Health Maintenance Organizations (HMOs), community and migrant health centers, industrial sites, occupational health centers, academic centers, private practice, the military, and federal government agencies.

The recent focus on emergency preparedness is also driving the demand for these skills.

Unfortunately, many experts have expressed concerns about the preparedness level of our public health workforce and its ability to respond to emergencies. The non-partisan, not-for-profit Trust for America's Health has published annual reports assessing America's public health emergency response capabilities. The most recent report, released in December 2008, found that neither state nor federal governments are adequately prepared to manage a public health emergency. One reason for this is a significant shortfall in funding needed to improve the nation's public health systems.<sup>7</sup>

Furthermore, the Centers for Disease Control and Prevention recently affirmed that there are significant holes in U.S. hospital emergency planning efforts for bioterrorism and mass casualty management.<sup>8</sup> These include varying levels of training among hospital staff for treating exposures to chemical, biological or radiological agents; lack of memoranda of understanding with supporting local health care facilities; and lack of preparedness training for explosive incidents. Yet, the skills needed to effectively prepare for and respond to bioterrorism and other public health threats—epidemiologic surveillance, disease prevention and containment, understanding and management of the health systems—are at the heart of preventive medicine training and public health practice. Preventive medicine training produces the public health leaders needed to effectively respond to today's threats to the public's health. A recent article on public health leadership trends showed that health department directors who were not physicians had difficulty handling serious outbreaks and other medical emergencies.<sup>9</sup>

#### **THE SUPPLY OF PREVENTIVE MEDICINE SPECIALISTS IS SHRINKING**

According to HRSA and health workforce experts, there are personnel shortages in many public health occupations, including among others, preventive medicine physicians, epidemiologists, biostatisticians, and environmental health workers.<sup>10</sup>

Exacerbating these shortages is a shrinking supply of physicians trained in preventive medicine:

- In 2002, *only 6,893* physicians self-designated as specialists in preventive medicine in the U.S., down from 7,734 in 1970. The percentage of total U.S. physicians self-designating as preventive medicine physicians decreased from 2.3% to 0.8% over that time period.<sup>11</sup>
- Between 1999 and 2006, the number of residents enrolled in preventive medicine training programs declined nearly 20%.<sup>12</sup>
- The number of preventive medicine residency programs decreased from 90 in 1999 to 71 in 2008-2009.<sup>12</sup>

ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. The decline in numbers is dramatic considering the existing critical shortage of physicians trained to carry out core public health activities. This deficiency will lead to major gaps in the expertise needed to deliver clinical prevention and community public health. The impact on the health of those populations served by HRSA may be profound.

### ***FUNDING FOR RESIDENCY TRAINING IS ERODING***

Physicians training in the specialty of Preventive Medicine, despite being recognized as an underdeveloped national resource and in shortage for many years, are the only medical residents whose graduate medical education (GME) costs are not supported by Medicare, Medicaid or other third party insurers. Training occurs outside hospital-based settings and therefore is not financed by GME payments to hospitals. Both training programs and residency graduates are rapidly declining at a time of unprecedented national, state, and community need for properly trained physicians in public health and disaster preparedness, prevention-oriented practices, quality improvement and patient safety. Both the Council on Graduate Medical Education and Institute of Medicine have called for enhanced training support.

Currently, residency programs scramble to patch together funding packages for their residents. Limited stipend support has made it difficult for programs to attract and retain high quality applicants; faculty and tuition support has been almost non-existent.<sup>13</sup> Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention).

The Health Resources and Services Administration (HRSA)—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs. HRSA funding (\$1.1 million in FY 2008) currently supports only 20 physicians in 5 preventive medicine training programs,<sup>14</sup> yet it ***represents the largest federal funding source*** for public health and general preventive medicine (PH/GPM) programs. ***Funding is in steady decline***; in FY 2002 the level was \$1.9 million.

These programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

- ***Forty percent*** of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate ***four times*** the average for all health professionals.<sup>4</sup> These physicians are meeting a critical need in these underserved communities.
- ***One-third*** of preventive medicine residents funded through HRSA programs are under-represented minorities, which is three times the average of minority representation among all health professionals.<sup>4</sup> Increased representation of minorities is critical because (1) under-represented minorities tend to practice in medically underserved areas at a higher rate than non-minority physicians, and (2) a higher proportion of minorities contributes to high quality, culturally competent care.
- ***Fourteen percent*** of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty<sup>16</sup>.

### **THE BOTTOM LINE: A STRONG, PREPARED, PUBLIC HEALTH SYSTEM REQUIRES A STRONG PREVENTIVE MEDICINE WORKFORCE**

The growing threats of a flu pandemic, disasters, and terrorism has thrust public health into the forefront of the nation's consciousness. ACPM applauds recent investments in disaster planning, information technology, laboratory capacity, and drug and vaccine stockpiles. However, any efforts to strengthen the public health infrastructure and disaster response capability must include measures to strengthen the existing training programs that help produce public health leaders.

Many of the public health leaders who guide the nation's public health response in the aftermath of the September 11 attacks and the recent hurricane disasters were physicians trained in preventive medicine. According to William L. Roper, MD, MPH, Dean of the School of Public Health, The University of North Carolina at Chapel Hill, *"Investing in public health preparedness and response without supporting public health and preventive medicine training programs is like building a sophisticated fleet of fighter jets without training the pilots to fly them."*

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### **REFERENCES**

- <sup>1</sup> Berrino F Role of Prevention: Cost Effectiveness of Prevention. *Annals of Oncology* 2004; 15:iv245-iv248.
- <sup>2</sup> Eijkemans G, Takala J. Moving Knowledge of Global burden into Preventive Action. *American Journal of Industrial Medicine* 2005; 48:395-399.
- <sup>3</sup> Ortegon M, Redekop W, Niesen L. Cost-Effectiveness of Prevention and Treatment of the Diabetic Foot. *Diabetes Care* 2004; 27:901-907.
- <sup>4</sup> Biviano M. Public Health and Preventive Medicine: What the Data Shows. Presented at the 9<sup>th</sup> Annual Preventive Medicine Residency Program Directors Workshop, San Antonio, Texas. HRSA. 2002.
- <sup>5</sup> Glass JK. Physicians in the Public Health Workforce. In Update on the Physician Workforce. Council on Graduate Medical Education. 2000.
- <sup>6</sup> Sabharwal R. Trends in Medical School Graduates' Perceptions of Instruction in Population-Based Medicine. In Analysis in Brief. American Association of Medical Colleges. Vol. 2, No.1. January 2002.
- <sup>7</sup> Hearne S, Chrissie J, Segal L, Stephens T, Earls M. Ready or Not? Protecting the Public's Health from Diseases, Disasters, and Bioterrorism 2008; Trust for America's Health. [www.healthyamericans.org](http://www.healthyamericans.org).
- <sup>8</sup> Niska R, Burt C. Bioterrorism and mass casualty preparedness in hospitals: United States, 2003. Advance data from vital and health statistics; no 364. Hyattsville, MD: National Center for Health Statistics. 2005.
- <sup>9</sup> Kahn, LH. A Prescription for Change: The Need for Qualified Physician Leadership in Public Health. *Health Affairs* 2003; 22:241-8.
- <sup>10</sup> Health Professions and Nursing Education Coalition. Recommendation for Fiscal Year 2007. March 2006.
- <sup>11</sup> American Medical Association (AMA). Physician Characteristics and Distribution in the U.S. 2004, Table 5.2, p. 323.
- <sup>12</sup> AMA. Graduate Medical Education Database. Copyright 1994-2005, Chicago, IL.
- <sup>13</sup> Magee JH. Analysis of Program Data for Preventive Medicine Residencies in the United States: Report to the Bureau of Health Resources & Services Administration. Washington, DC: American College of Preventive Medicine, 1997.
- <sup>14</sup> <http://bhpr.hrsa.gov/publichealth/preventive/index.htm>. Preventive Medicine Residency Training Grants.
- <sup>15</sup> Training Physicians for Public Health Careers. Institute of Medicine. National Academies Press, June 2007.
- <sup>16</sup> Percentage of ACGME Residents/Fellows Who are Black, Native American or Native Hawaiian by Specialty. AAMC/AMA National GME census, October 2008.

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**The National Violent Death Reporting System (NVDRS): Linking Data. Saving Lives**

Each year, 50,000 Americans die violent deaths. Homicide and suicide are, respectively, the third and fourth leading causes of death for people aged 1–39 years. An average of 80 people take their own lives every day.

Before the National Violent Death Reporting System (NVDRS) was created, federal and state public health and law enforcement officials collected valuable information about violent deaths, but lacked the ability to combine it into one comprehensive reporting system. Instead, data was held in a variety of different systems, and policymakers lacked the clear picture necessary to develop effective violence prevention policies.

When it was created in 2002, NVDRS promised to capture data that is critical to identifying patterns and developing strategies to save lives. With a clearer picture of why violent deaths occurs, law enforcement and public health officials can work together more effectively to identify those at risk and provide effective preventive services.

Currently, NVDRS funding levels only allow the program to operate in the following 17 states: Alaska, California, Colorado, Georgia, Kentucky, Maryland, Massachusetts, New Jersey, New Mexico, North Carolina, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia, and Wisconsin. Nine additional states, plus the District of Columbia were previously approved for participation in the NVDRS, but were unable to join due to funding shortfalls: Connecticut, Illinois, Maine, Michigan, Minnesota, New York, Ohio, and Texas. Several other states have expressed an interest in joining once new funding becomes available.

While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 17 participating states, many other states have been forced to sit idle until additional funding is allocated. With the inclusion of \$7.5 million for NVDRS in FY 2010, NVDRS will be able to expand to additional states and continue its incremental growth toward national implementation.

**NVDRS Provides Critical Data for Suicide Prevention**

Although it is preventable, more than 30,000 Americans die by suicide each year, and another 1.8 million Americans attempt it, costing more than \$3.8 billion in hospital expenses and \$13 billion in lost earnings.

In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths – include deaths by suicide – information from the system can be used to develop effective suicide prevention plans at the community, state, and national level.

Among the ways NVDRS data is being used to inform suicide prevention programs: NVDRS data from 13 states uncovered significant racially- and ethnically-based differences in mental illness diagnoses and treatment among those who died by suicide. Specifically, whites were more likely to have been diagnosed with depression or bipolar disorder, while blacks were more likely than other groups to have been diagnosed with schizophrenia. Hispanics were less likely to have been diagnosed with a mental illness or to have received treatment at all, although the

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family reports of depression were comparable to other racial groups. Additionally, NVDRS data from all 17 states show that veterans accounted for 26 percent of males who died by suicide in 2004. While veterans also accounted for 26 percent of the male U.S. population, this finding points to the importance of veterans' services to potentially identify and treat at-risk individuals.

With such information available for the first time, officials in participating states are using NVDRS data in myriad ways. For example,

- With the sixth-highest rate of elder suicide in the nation, Oregon tailored its NVDRS data to develop an epidemiological profile of victims and establish an elder suicide prevention plan. NVDRS data indicated that most victims of elder suicide in Oregon had been suffering from physical illness, and that 37 percent had visited a doctor in the 30 days prior to their death. As a result of this NVDRS data, the state developed an elder suicide prevention plan that calls for better integration of primary care and mental health services, so that potential suicide victims can be better identified and treated. The plan also calls for training primary health care providers, integrating mental health care into primary care, and educating family members about the risks of suicide and warning signs of depression.
- NVDRS data found that one in four of Virginia's suicide victims had served in the military. Among male victims over 65, more than 60 percent were veterans. These findings indicate that the state's suicide prevention and education efforts must extend to veterans' hospitals and service providers.
- NVDRS data provides state health officials in South Carolina with vital information that indicates behavior patterns, enables health officials to identify individuals at risk, and to intervene early with appropriate preventive measures. After NVDRS data showed that more than 40 percent of suicide victims were currently or formerly receiving mental health treatment or tested positive for psychiatric medication, the state established its first ever suicide prevention plan, which also included the formation of a Suicide Prevention Task Force.

#### **NVDRS Provides Critical Data to Protect Children and Adolescents**

Child abuse and other violence involving children and adolescents remains a problem in America, and it is only through a comprehensive understanding of its root causes that many needless deaths can be prevented. Studies suggest that between 3.3 and 10 million children witness some form of domestic violence annually. Additionally, 1,387 children died as a result of abuse or neglect in 2004, according to the federal Administration on Children, Youth, and Families, part of the Department of Health and Human Services.

Children are most vulnerable and most dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their primary care environments. Combined NVDRS data from Alaska, Maryland, Massachusetts, New Jersey, Oregon, South Carolina, and Virginia determined that African American children four years old and under are more than four times more likely to be victims of homicide than Caucasian children, and that homicides of children four and under are most often



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committed by a parent or caregiver in the home. The data also shows that household items, or “weapons of opportunity,” were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of abusers can lead to more effective, targeted prevention programs.

Other examples of how NVDRS data is informing programs to protect children and adolescents from violence, include the following:

- Data from NVDRS pilot sites in Connecticut, Maine, Utah, Wisconsin, Pennsylvania, and California found that almost 30 percent of suicide victims age 17 and under told someone they felt suicidal. Many teen suicides also appear to be linked to recent events in their lives, with nearly one-third of suicides taking place on the same day as a crisis and almost half within the same week. This data underscores the importance of developing community-based programs to rapidly respond to the warning signs of suicide.
- With data generated by NVDRS, state health officials in Massachusetts have been able to monitor suicides and homicides more accurately among specific populations, such as foster children and youths in custody. The NVDRS data has been used to secure grants for violence prevention programs for these special populations, about whom data had previously been impossible to obtain.

#### **NVDRS Provides Critical Data to Prevent Intimate Partner Violence**

While intimate partner violence (IPV) has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. Women are much more likely than men to be killed by an intimate partner. Intimate partner homicides accounted for 33.5 percent of the murders of women and less than four percent of the murders of men in 2000, according to the Bureau of Justice Statistics.

Although the program is still in its early stages, NVDRS is providing critical information that is helping law enforcement and health and human service officials allocate resources and develop programs in ways that target those most at risk for intimate partner violence, thereby preventing needless deaths. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect, and a substantial number of victims were the suspect’s children. In addition, NVDRS indicates that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and the majority of these incidents occurred in the women’s homes.

Examples of how state officials are using NVDRS data to better understand and prevent intimate partner violence include:

- Based on an analysis of NVDRS data, the Kentucky Injury Prevention Research Center concluded that among women killed by an intimate partner, only 39% had had filed for a restraining order or been seen by or reported to Adult Protective Services. This finding underscored a perceived need in the community to improve outreach linking potential victims to local protective services.

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- Working with the state's NVDRS program, the Alaska Department of Law and Public Safety found there is a high risk for intimate partner violence, both homicide and suicide, when one partner is attempting to leave the relationship. Findings such as this one are molding the state's strategy for domestic violence prevention.

#### **Strengthening and Expanding NVDRS in FY 2010**

At an estimated annual cost of \$20 million for full implementation, NVDRS is a relatively low-cost program that yields high-quality results. While state-specific information provides enormous value to local public health and law enforcement officials, national data from all 50 states, the U.S. territories and the District of Columbia must be obtained to complete the picture and establish effective national violence prevention policies and programs.

That is why the National Violence Prevention Network, a coalition of national organizations who advocate for health and welfare, violence and suicide prevention, and law enforcement, is calling on Congress to provide no less than \$7.5 million for NVDRS for FY 2010. The cost of *not* implementing the program is much greater: without national participation in the program, thousands of American lives remain at risk.

The following organizations — representing a diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates — urge Congress to provide at least \$7.5 million to strengthen and expand the National Violent Death Reporting System in FY 2010:

Ambulatory Pediatric Association  
American Academy of Pediatrics  
American Association of Suicidology  
American College of Emergency Physicians  
American College of Physicians  
American College of Preventive Medicine  
American Pediatric Society  
American Psychiatric Association  
American Psychological Association  
American Public Health Association  
Association of Medical School Pediatric Department Chairs  
Child Welfare League of America  
Children's Healthcare Is a Legal Duty (CHILD)  
Children's Safety Network Economics and Data Analysis Resource Center  
Coalition for American Trauma Care  
Council of State and Territorial Epidemiologists  
Emergency Nurses Association  
Family Violence Prevention Fund  
National Association of County & City Health Officials  
National Association of Medical Examiners  
National Association of Pediatric Nurse Practitioners

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National Black Police Association  
National Organization of People of Color Against Suicide  
National School Safety Center  
New York Academy of Medicine  
The Police Foundation  
Society for Adolescent Medicine  
Society for Pediatric Research  
Society for Public Health Education  
State and Territorial Injury Prevention Directors Association  
Suicide Awareness/Voices of Education (SAVE)  
Suicide Prevention Action Network USA (SPAN USA)  
Voices for America's Children

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**Testimony of  
Janel Wright  
Chair, Advocacy Committee  
American Diabetes Association**

**To the United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, and Education**

**May 1, 2009**

**Contact:  
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703-253-4363  
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Thank you for the opportunity to provide this testimony to the Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. As someone who has lived with diabetes for over thirty years, I am pleased to have the opportunity to submit testimony on behalf of the American Diabetes Association.

I write to you as a representative of the 80 million American adults and children living with diabetes or pre-diabetes. In the five minutes it will take you to read my testimony 15 more Americans will be diagnosed with diabetes. Today is not a good day for people with diabetes: 230 people with diabetes will undergo an amputation, 120 people will enter end-stage kidney disease programs, and 55 people will go blind due to diabetes. Today diabetes will cost our country nearly a half a billion dollars. That is what happened yesterday, today, and will happen again tomorrow. Yet, it is but a fraction of what lies ahead unless we take action. The purpose of my testimony is to urge Congress to invest in research and prevention efforts proportionate to the magnitude of the burden diabetes has on our country and, by doing so, to change the future of diabetes in America.

As the nation's leading non-profit health organization providing diabetes research, information and advocacy, the American Diabetes Association believes federal funding for diabetes prevention and research is critical, not only for the 23.6 million American adults and children (nearly 8 percent of the population) who currently have diabetes, but for the 57 million more with pre-diabetes. Of the 23.6 million, 6 million are unaware they have diabetes. Together, this means that 25 percent of the U.S. population either has, or is at risk for developing, this serious disease. Federal funding for diabetes prevention and research efforts is critical to reversing this epidemic.

Diabetes is a chronic condition that impairs the body's ability to use food for energy. The hormone insulin, which is made in the pancreas, helps the body change food into energy. In people with diabetes, the pancreas either does not create any insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. If left untreated, diabetes results in too much glucose in the blood stream. The majority of diabetes cases, 90 to 95 percent are type 2, while type 1 diabetes accounts for five to ten percent of diagnosed cases. The complications of diabetes are widespread and serious. In those with pre-diabetes, blood glucose levels are higher than normal and taking action to reduce their risk of developing diabetes is essential.

The Centers for Disease Control and Prevention (CDC) has identified diabetes as an epidemic that is disabling, deadly, and on the rise. According to the CDC, one in three children born in the year 2000 is likely to develop the disease in their lifetime if current trends continue. This number is even greater among minority populations, where nearly one in two children will develop diabetes. Between 1990 and 2001, the prevalence of diabetes increased by 60 percent. Additionally, type 2 diabetes, traditionally seen in older patients, is beginning to reach a younger population, due in part to the surge in childhood obesity.

The impact diabetes has on individuals and the health care system is enormous and continues to grow at a shocking rate. Diabetes is a leading cause of kidney disease, adult-onset blindness and lower limb amputations as well as a significant cause of heart disease and stroke. Since 1987, the death rate due to diabetes has increased by 45 percent. In that same period, death rates for heart disease, stroke and cancer have dropped.

In addition to the physical toll, diabetes also attacks our pocketbooks. The American Diabetes Association estimates the direct and indirect cost of diagnosed diabetes in 2007 exceeded \$174 billion. That year, medical expenditures due to diabetes totaled \$116 billion, including \$27 billion for diabetes care, \$58 billion for chronic diabetes-related complications, and \$31 billion for excess general medical costs. Indirect costs resulting from increased absenteeism, reduced productivity, disease-related unemployment disability and loss of productive capacity due to early mortality totaled \$58 billion. This is an increase of 32 percent since 2002. Thus, in just five years, the cost of diabetes increased by \$42 billion, or \$8 billion per year. In fact, approximately one out of every five health care dollars is spent caring for someone with diagnosed diabetes, while one in ten health care dollars is attributed to diabetes. Additionally, one-third of Medicare expenses are associated with treating diabetes and its complications. Other studies have shown the cost of pre-diabetes, undiagnosed diabetes and gestational diabetes add another \$44 billion in diabetes-costs, bringing the annual burden of diabetes-related costs to \$218 billion.

Despite these numbers, there is hope. A strong commitment to funding for the diabetes prevention work being done at the Division of Diabetes Translation (DDT) at the Centers for Disease Control and Prevention (CDC) and research at the National Institute of Diabetes and Digestive Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) is crucial for finding a cure and improving the lives of those living with, or at risk for, diabetes. In this vein, for Fiscal Year 2010, the American Diabetes Association is requesting:

- \$89.4 million for the CDC's Division of Diabetes Translation. This represents an increase of \$23.6 million, or one dollar for every American with diabetes. We are grateful for the modest increase that DDT received under the Omnibus Appropriations Act for fiscal year 2009, but due to the scope of the diabetes epidemic, it is clear that further action is necessary.
- \$1.884 billion for the National Institute of Diabetes and Digestive and Kidney Diseases, an increase of seven percent over the fiscal year 2009 level. This, in addition to funds appropriated for NIH in the American Recovery and Reinvestment Act, will act to offset years of stagnant funding and inflation that caused cutbacks to promising research. It will also demonstrate Congress' commitment to science and research.

### **CDC's Division of Diabetes Translation**

CDC's DDT works to eliminate the preventable burden of diabetes through research, education, and by translating science into clinical practice. Funds appropriated to DDT focus on defining the diabetes burden through the use of public health surveillance; translating research findings into clinical and public health practice; developing and maintaining state-based diabetes and prevention programs; and supporting the National Diabetes Education Program (NDEP). Our request of an additional \$23.6 million will allow these critical programs at DDT to reach more at risk Americans and help to prevent or delay this destructive disease.

DDT is able to translate important research findings, including the results of clinical trials and scientific studies, and identify the public health implications of the research. These findings are applied in health care systems and within local communities. Areas of translational research include access to quality care for diabetes; cost-effectiveness of diabetes prevention and control activities; effectiveness of health practices to address risk factors for diabetes; and demonstration of primary prevention of type 2 diabetes. One example of a highly successful translational effort by DDT is the Diabetes Prevention Program Initiative (DPPI), a structured lifestyle intervention modeled after the Diabetes Prevention Program (DPP) clinical research study. The DPPI is proving that a group lifestyle intervention can lower diabetes risk while being delivered in a cost effective way in a community setting.

Another important component of DDT's efforts is the national surveillance system. The system provides comprehensive diabetes data at the national, state, and local levels so that analysts may better track the epidemic. Additionally, some of DDT's most important efforts are based within the Diabetes Prevention and Control Programs (DPCPs) in all 50 states, the District of Columbia, and 8 other territories. DPCPs work to not only reduce the incredible burden of diabetes, but to make certain the people they serve are fully aware of the disease and those with or at risk of developing diabetes are receiving the highest quality of care possible. Because they are community based, DPCPs are highly adaptable and capable of reaching those at greatest risk in a given area. These programs provide an essential infrastructure to coordinate diabetes prevention and control efforts, but a severe lack of funding leaves DPCPs unable to reach all of those who could benefit from their work.

### **NIH's National Institute of Diabetes and Digestive Kidney Diseases**

One of the 27 institutes housed at the National Institutes of Health, the National Institute of Diabetes and Digestive Kidney Diseases (NIDDK), is poised to make major discoveries that could prevent diabetes, better treat its complications, and – ultimately – find a cure. Researchers at NIH are working on a variety of projects that represent hope for the millions of individuals with both type 1 and type 2 diabetes. The list of advances in treatment and prevention is long, but it is important to understand much more can be achieved for people with diabetes with an increased investment in scientific research at NIDDK.

Researchers have already learned a great deal about the biology of diabetes, and they now understand much more about the loss of islet cell function. These discoveries have led directly to islet cell transplants and ongoing work to extend the life of transplanted cells. Thanks to research at NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. The result is the ability to live healthier lives with diabetes.

The NIDDK funded the Diabetes Prevention Program, a multicenter clinical research trial that found modest weight loss through dietary changes and increased physical activity could prevent or delay the onset of type 2 diabetes by 58 percent. Other recent discoveries at NIDDK include the ability to predict type 1 diabetes risk, new drug therapies for type 2 diabetes, and the discovery of genetic markers that explain the increased burden of kidney disease among African Americans.

#### **Conclusion**

As you consider the Fiscal Year 2010 appropriation for DDT and NIDDK, we ask that you consider that diabetes is an epidemic that it is growing at an astonishing rate. If left unchecked, diabetes will undoubtedly overwhelm the healthcare system with tragic economic and socioeconomic consequences. To change this future we need to increase our commitment to research and prevention in a way that reflects the burden that diabetes poses both for us and for our children.

Through important DDT programs we have the chance to drastically reduce the number of people with diabetes. Given the astounding costs of diabetes, the request of \$89.4 million for DDT is a small investment to make in our future. A seven percent increase in NIH funding opens the door to research opportunities that will both improve patient outcomes and reduce the economic cost of diabetes.

Much more needs to be done to expand our fight against diabetes. Your continued leadership in combating this growing epidemic is essential to make meaningful progress in stemming the tide of diabetes and its complications. Thank you for your commitment to the diabetes community and for the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.



**STATEMENT BY THE AMERICAN HEART ASSOCIATION**  
**TIMOTHY GARDNER, M.D., PRESIDENT**  
 202-785-7900 [claudia.louis@heart.org](mailto:claudia.louis@heart.org)  
**FY 2010 APPROPRIATIONS FOR LABOR-HHS-EDUCATION**  
 (NIH, CDC, HRSA, AHRQ)

Despite considerable progress, heart disease, stroke and other forms of cardiovascular disease remain major causes of permanent disability and our Nation's No. 1 and most costly killer, with a death every 37 seconds. Cardiovascular disease will cost our country a projected \$475 billion in medical costs and lost productivity this year. Heart disease, alone, is our leading cause of death and stroke is our No. 3 killer.

In the face of these staggering statistics, heart disease and stroke research, treatment and prevention programs remain woefully underfunded. For example, National Institutes of Health (NIH) invests only 4 percent of its budget on heart research and a mere 1 percent on stroke research. This level of funding is not commensurate with scientific opportunities, the number afflicted and the economic toll exacted on our Nation.

Cardiovascular disease remains the No. 1 killer in every state and many preventable and treatable risk factors continue to escalate. Unfortunately, the Centers for Disease Control and Prevention (CDC) has been able to provide basic implementation awards to only 14 states through its Heart Disease and Stroke Prevention Program and only 20 states are funded for CDC's WISEWOMAN, a heart disease and stroke screening program for low income uninsured and under-insured females. Moreover, where you live could affect whether you survive a particularly deadly form of heart disease, sudden cardiac arrest. At present, only 12 states receive funding for the Health Resources and Services Administration's Rural and Community Access to Emergency Devices Program designed to save lives from sudden cardiac death.

The American Heart Association appreciates Congress providing hope to the 1 in 3 adults in the United States who live with the consequences of cardiovascular disease, with the enactment of the American Recovery and Reinvestment Act and the FY 2009 Omnibus Appropriations Act. The Association commends Congress for including \$10 billion for the NIH and \$1 billion for a Prevention and Wellness Fund in the ARRA. These are wise and prudent investments that will provide both a much needed boost to our Nation's economy and enhance health. Yet these funds represent a one-time infusion of resources. Stable and sustained funding is imperative to boost heart disease and stroke prevention and treatment.

**FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION**

With numerous new and promising research opportunities on the horizon and with cardiovascular disease risk factors on the rise, now is the time to make a wise enhanced investment to prevent and treat America's No. 1 and most costly killer. If Congress fails to capitalize on progress against cardiovascular disease now, Americans will pay more in the future in lost lives and higher health care costs. Our recommendations listed below address these issues in a comprehensive but fiscally responsible way follow.

<b><u>Summary of Recommendations</u></b>	
National Institutes of Health	\$32.4 billion
National Heart, Lung, and Blood Institute	\$3.2 billion
National Institute of Neurological Disorders and Stroke	\$1.7 billion
Agency for Healthcare Research and Quality	\$405 million
Centers for Disease Control and Prevention	\$8.6 billion
Heart Disease and Stroke Prevention Program	\$74 million
WISEWOMAN	\$37 million
National Center for Health Statistics	\$152.5 million*
Health Resources and Services Administration	
Rural and Community Access to Emergency Devices Program	\$8.9 million
*Includes \$137.5 million in base funding plus \$15 million in one-time funding for vital statistics system infrastructure improvement	

#### **Funding Gap for the National Institutes of Health (NIH)**

NIH research has revolutionized patient care and holds the key to finding new ways to prevent, treat and cure cardiovascular disease, resulting in longer, healthier lives and reduced health care costs. NIH invests resources in every state and in 90% of congressional districts.

***The American Heart Association Recommends:*** AHA supports the President's campaign pledge to double the NIH budget over the next decade. We advocate for a FY 2010 appropriation of \$32.4 billion for NIH, a 7% increase over the FY 2009 appropriation, representing the first installment to double the NIH budget by FY 2020. The economic stimulus increase for the NIH makes good economic sense, but stable and sustained funding is needed to help secure a solid return on Congress' investment that has saved millions of lives. NIH supported research prevents and cures disease and generates economic growth, creates jobs and preserves the U.S. role as the world leader in pharmaceuticals and biotechnology. Each NIH grant is associated with approximately seven jobs.

#### **Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment**

Death rates from coronary heart disease and stroke have each fallen by almost 30 percent since 1999. This decline in cardiovascular disease death rates is directly related to NIH heart and stroke research, with scientists on the verge of new and exciting discoveries that could lead to innovative treatments and even cures for heart disease and stroke. For instance, recent NIH research has shown that post-menopausal hormone therapy does not prevent heart disease and

stroke, has defined the genetic basis of dangerous responses to vital blood-thinners, and funded early work of the 2007 Nobel Prize winners in Physiology or Medicine for development of gene targeting technology.

In addition to saving lives, NIH-supported research can cut health care costs. For example, the original NIH tPA drug trial resulted in a 10-year net \$6.47 billion reduction in stroke health care costs. The Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net saving of \$1.27 billion. But, despite such concrete returns on investments and other successes, NIH heart and stroke research continues to be disproportionately under-funded, with NIH spending only 4% of its budget on heart research, and a mere 1% on stroke research. NIH funding for these diseases are not commensurate with scientific opportunities, the number afflicted, the increasing prevalence, and the economic toll exacted on our Nation.

**Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)**

Cardiovascular disease research funding fails to keep pace with medical research inflation and cannot sufficiently support existing studies or permit investment in promising research opportunities. The sustained loss of purchasing power has reduced NHLBI's ability to support investigator-initiated research and has forced cuts in Institute programs. Cutbacks will limit the implementation of both the NHLBI general and cardiovascular-specific strategic plans. Studies that could be scaled back include, the translation of basic research on human behavior into real world ways to reduce obesity and promote cardiovascular health; research on genetic susceptibility to heart disease in the Framingham population followed for three generations, and additional research into the best methods for saving lives of sudden cardiac arrest sufferers.

**Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)**

An estimated 795,000 Americans will suffer a stroke this year, and more than 137,000 will die. Many of the 6.5 million stroke survivors face physical and mental disabilities, emotional distress and huge costs—a projected \$69 billion in medical expenses and lost productivity in 2009.

The NINDS-sponsored Stroke Progress Review Group has issued a long-term, stroke research strategic plan. A variety of research initiatives have since been undertaken, but more funding is needed to fully implement the plan. The FY 2009 estimate for NINDS stroke research falls about 60% short of the plan's target and additional funding is needed for programs such as:

- *Stroke Translational Research* – Translational studies are essential to providing cutting-edge stroke treatment, patient care and prevention. However, due to budget shortfalls, NINDS has been forced to scale back by 30% its Specialized Programs of Translational Research in Acute Stroke from a planned 10 centers to only seven.
- *Genetic Repository* – NINDS could better understand genetic risk factors associated with stroke by helping more researchers contribute data and findings to an NIH-funded genetic repository and to study available samples.
- *Neurological Emergencies Treatment Trials Network* – NINDS has established a clinical research network of emergency medicine physicians, neurologists and neurosurgeons to develop more and improved treatments for acute neurological emergencies, such as strokes. However, the number of trials will be limited by available funding.

***The American Heart Association Recommends:*** AHA supports an FY 2010 appropriation of \$3.227 billion for the NHLBI; and \$1.705 billion for the NINDS. These funding levels represent a 7% increase over FY 2009—comparable to the Association’s overall recommended percentage increase for the NIH.

**Increase Funding for the Centers for Disease Control and Prevention (CDC)**

Prevention is the best way to protect the health of Americans and reduce the economic burden of heart disease and stroke. However, effective prevention strategies and programs are not being implemented due to insufficient federal resources.

For example, despite the fact that cardiovascular disease remains the No. 1 killer in every state, CDC’s Division for Heart Disease and Stroke Prevention funds only 14 states to implement programs to reduce risk factors for heart disease and stroke, improve emergency response and quality care, and end treatment disparities. Another 27 states receive funds for capacity building (planning); but, there are no funds for actual implementation and many of these states have been stalled in the planning phase for years—some for a decade.

This Division also administers the WISEWOMAN program that screens uninsured and under-insured low-income women ages 40 to 64 in 20 states for heart disease and stroke risk. They receive counseling, education, referral and follow-up as needed. Since January 2000, more than 84,000 women have been screened and more than 210,000 lifestyle interventions have been conducted. An estimated 94% of these women were found to have at least one risk factor or pre-condition for heart disease, stroke or other forms of cardiovascular disease. This program should be expanded to the other 30 states and to screen more eligible women in currently funded states.

***The American Heart Association Recommends:*** AHA joins with the CDC Coalition in support of an appropriation of \$8.6 billion for CDC core programs, including increases for the Heart Disease and Stroke Prevention and WISEWOMAN programs. Within that total, we recommend \$74 million for the Heart Disease and Stroke Prevention Program, allowing CDC to: (1) add the nine unfunded states; (2) elevate up to 18 states with capacity building (planning) awards to basic program implementation; (3) continue to support the remaining funded states; (4) maintain the Paul Coverdell National Acute Stroke Registry; (5) increase the capacity for national, state and local heart disease and stroke surveillance; and (6) provide additional assistance for prevention research and program evaluation. AHA also advocates \$37 million to expand WISEWOMAN to additional states. During last year’s national competition, 10 states received approved applications but were denied funding due to insufficient federal resources. And, we join with the Friends of the NCHS in recommending \$137.5 million for NCHS and one-time funding of \$15 million to support states to modernize the vital statistics system.

**Restore Funding for Rural and Community Access to Emergency Devices (AED) Program**

About 92% of cardiac arrest victims die outside of a hospital. Receiving immediate CPR and the use of an AED can more than double your chance of survival. Communities with comprehensive AED programs have achieved survival rates of 40% or higher. The Rural and Community AED Program provides grants to states to buy and place AEDs and train lay rescuers and first responders to use them. During its first year, 6,400 AEDs were purchased, and placed and 38,800 individuals were trained. Due to budget cuts, only 12 states receive resources for this program.

***The American Heart Association Recommends:*** For FY 2010, AHA advocates restoring the Rural and Community AED Program to its FY 2005 level of \$8.927 million.

**Increase Funding for the Agency for Healthcare Research and Quality (AHRQ)**

AHRQ develops scientific evidence to improve health and health care. Through its *Effective Health Care Program*, AHRQ supports research focused on outcomes, comparative effectiveness and the appropriateness of pharmaceuticals, devices and health care services for conditions such as heart disease, stroke and high blood pressure.

On another front, AHRQ's health information technology (HIT) plan will help bring health care into the 21st century through more than \$260 million invested in over 200 projects and demonstrations since 2004. AHRQ and its partners identify challenges to HIT adoption and use; develop solutions and best practices; and produce tools that help hospitals and clinicians successfully integrate HIT. This work must continue as a key component to health reform.

***The American Heart Association Recommends:*** AHA joins with Friends of AHRQ in advocating for a \$405 million in base funding for AHRQ. It will preserve AHRQ's current initiatives and get the agency on track to a base budget of \$500 million by 2013.

#### CONCLUSION

Heart disease, stroke and other forms of cardiovascular disease continue to impose a deadly, disabling and costly burden on Americans. However, a robust funding increase for NIH, CDC and HRSA research, treatment and prevention programs will continue to save lives and reduce rising health care costs. The American Heart Association urges Congress to give serious consideration to our recommendations during the FY 2010 congressional appropriations process. They are a wise investment for our nation and the health and well-being of all Americans now and in future generations.

AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM  
STATEMENT SUMMARY SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES  
COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES

May 1, 2009

**Summary of Requests:** Summarized below are the Fiscal Year 2010 (FY 2010) recommendations for the nation's 36 Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

**DEPARTMENT OF EDUCATION PROGRAMS:**

**A. Higher Education Act Programs:**

- **Strengthening Developing Institutions:** Section 316 of Title III-A, specifically supports TCUs through two separate grant programs: a) formula funded development grants, and b) competitive facilities/construction grants designed to address the critical facilities needs at TCUs. The TCUs request that the Subcommittee appropriate \$32.0 million to support these two vital programs.
- **Pell Grants:** TCUs urge the Subcommittee to fund the Pell Grant Program at the highest possible level.

**B. Perkins Career and Technical Education Programs:** The TCUs urge the Subcommittee to appropriate \$8.5 million for Sec. 117 of the Carl D. Perkins Career and Technical Education Improvement Act, which supports our two Tribally Controlled Postsecondary Vocational Institutions: United Tribes Technical College and Navajo Technical College. Additionally, TCUs strongly support the Native American Career and Technical Education Program (NACTEP) authorized under Sec. 116 of the Act.

**C. Relevant Title IX Elementary and Secondary Education Act (ESEA) Programs:**

- **Adult and Basic Education:** Although federal funding for tribal adult education was eliminated in Fiscal Year 1996, TCUs continue to offer much needed adult education, GED, remediation and literacy services for American Indians, yet their efforts cannot meet the demand. *The TCUs request that the Subcommittee direct \$5.0 million of the Adult Education State Grants appropriated funds to make awards to TCUs to support their ongoing and essential adult and basic education programs.*
- **American Indian Teacher and Administrator Corps:** The American Indian Teacher Corps and the American Indian Administrator Corps offer professional development grants designed to increase the number of American Indian teachers and administrators serving their reservation communities. *The TCUs request that the Subcommittee support these programs at \$10.0 million and \$5.0 million, respectively.*

**DEPARTMENT OF HEALTH and HUMAN SERVICES PROGRAM:**

**D. Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF):** Tribal Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs are working to meet the mandate that Head Start teachers earn degrees in Early Childhood Development or a related discipline. *The TCUs request that \$5.0 million be designated for the TCU-Head Start Partnership program, to ensure the continuation of current programs and the resources needed to support additional TCU-Head Start Partnership programs.*

**STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM  
SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES - COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES**

May 1, 2009

Mr. Chairman and Members of the Subcommittee, on behalf of this nation's 36 Tribal Colleges and Universities (TCUs), which compose the American Indian Higher Education Consortium (AIHEC), thank you for the opportunity to share our Fiscal Year 2010 (FY 2010) funding recommendations for programs within the U.S. Department of Education and the U.S. Department of Health and Human Services - Head Start program.

This statement will cover two areas: a) background on the Tribal Colleges and Universities (TCUs), and b) justifications for our funding recommendations.

**I. Background on Tribal Colleges and Universities**

The Tribal College Movement began in 1968 with the establishment of Navajo Community College, now Diné College, in Tsaile, Arizona. Rapid growth of tribal colleges soon followed, primarily in the Northern Plains region. In 1972, the six original tribally controlled colleges established AIHEC to provide a support network for member institutions. Today, AIHEC represents 36 Tribal Colleges and Universities located in 14 states, which were begun specifically to serve the higher education needs of American Indians. Annually, these institutions serve students from more than 250 federally recognized tribes, more than 80 percent of whom are eligible to receive federal financial aid.

Tribal Colleges and Universities are accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide essential high school completion (GED), basic remediation, job training, college preparatory courses, and adult education programs. TCUs fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public meeting places, and child and elder care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal Colleges and Universities provide access to higher education for American Indians and others living in some of the nation's most rural and economically depressed areas. According to 2000 Decennial Census data, the annual per capita income of the U.S. population was \$21,587. In contrast, the annual per capita income of Native Americans was \$12,893 or about 40 percent less. In addition to serving their student populations, TCUs offer a variety of much needed community outreach programs.

These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs effectively blend traditional teachings with conventional postsecondary curricula. They have developed innovative ways to address the needs of tribal populations and are overcoming long-standing barriers to success in higher education for American Indians. Since the first TCU was established on the Navajo Nation in 1968, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to, and promoting achievement among, students who may otherwise never have known postsecondary education success.

Despite their remarkable accomplishments, TCUs remain the most poorly funded institutions of higher education in the country. Chronic lack of adequate funds remains the most significant barrier to their expanded success. Funding for the institutional operating budgets of 25 reservation-based TCUs is provided under Title I of the Tribally Controlled College or University Assistance Act (P.L. 95-471). Currently, the institutional operating budgets of these colleges are funded at \$5,494 per Indian student -- only enrolled members of a federally recognized tribe or the biological child of a tribal member may be counted as Indian students for the purpose of determining an institution's operations funding level. Because TCUs are located on federal trust land, states have no obligation to fund them -- not even for the non-Indian state-resident students who account for approximately 20 percent of TCU enrollments. Yet, if these same students attended any other public institution in the state, the state would provide basic operating funds to the institution. While mainstream public institutions have had a foundation of stable state tax-based support, TCUs must rely on annual federal appropriations for their day-to-day institutional operating budgets. In 30 years, since the Tribal College Act was initially funded, these reservation-based colleges have never received the authorized funding level for their institutional operations. In fact, they have lost ground. When you consider inflation over that time period, TCUs would need to receive an additional \$1,115 per Indian student to reach \$6,609, the level necessary to simply secure the same buying power they received in their initial appropriation in FY 1981, which was \$2,831 per Indian student. This is not simply a matter of appropriations falling short of an authorization. It effectively impedes the TCUs from having the resources necessary to provide educational services afforded students at state-funded institutions of higher education.

Inadequate funding has left many TCUs with no choice but to continue to operate under severely distressed conditions. The need remains urgent for construction, renovation, improvement, and maintenance of key TCU facilities, such as basic and advanced science laboratories, computer labs, and increasingly important student housing, day care centers, and community service facilities. Although the situation has improved dramatically at many TCUs in the past several years, some TCUs still operate -- at least partially -- in donated and temporary buildings. Few have dormitories, even fewer have student health centers and only one TCU has a science research laboratory.

As a result of more than 200 years of federal Indian policy -- including policies of termination, assimilation and relocation -- many reservation residents live in conditions of poverty comparable to that found in Third World nations. Through the efforts of TCUs, American Indian communities are availing themselves of resources needed to foster responsible, productive, and self-reliant citizens.

## **II. Justifications**

### **A. Higher Education Act**

The Higher Education Act Amendments of 1998 created a separate section (§316) within Title III-A specifically for the nation's Tribal Colleges and Universities. Programs under Titles III and V of the Act support institutions that enroll large proportions of financially disadvantaged students and that have low per-student expenditures. Tribal colleges, which are truly developing institutions, are providing access to quality higher education opportunities to some of the most rural, impoverished, and historically underserved areas of the country. A clear goal of the Higher Education Act Title III programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to



effectively prepare them to succeed in a global, competitive workforce. *The TCUs urge the Subcommittee to appropriate \$32.0 million in FY 2010 for Title III-A section 316, an increase of \$8.8 million over FY 2009. These funds will afford these developing institutions the resources necessary to continue their ongoing grant programs and address the needs of their historically underserved students and communities.*

The importance of Pell Grants to TCU students cannot be overstated. U.S. Department of Education figures show that the majority of TCU students receive Pell Grants, primarily because student income levels are so low and our students have far less access to other sources of financial aid than students at state-funded and other mainstream institutions. Within the tribal college system, Pell Grants are doing exactly what they were intended to do -- they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. *The TCUs urge the Subcommittee to fund this critical grants program at the highest possible level.*

#### **B. Carl D. Perkins Career and Technical Education Act**

**Tribally-Controlled Postsecondary Vocational Institutions:** Section 117 of the Perkins Act provides operating funds for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. *The TCUs urge the Subcommittee to appropriate \$8.5 million for Sec. 117 of the Act.*

**Native American Career and Technical Education Program:** The Native American Career and Technical Education Program (NACTEP) under Sec. 116 of the Act reserves 1.25% of appropriated funding to support Indian vocational programs. *The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of much needed vocational education programs being offered at Tribal Colleges and Universities.*

#### **C. Greater Support of Indian Education Programs**

**American Indian Adult and Basic Education (Office of Vocational and Adult Education):** This program supports adult basic education programs for American Indians offered by TCUs, state and local education agencies, Indian tribes, institutions, and agencies. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those American Indians that the present K-12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The number of students in need of remedial education before embarking on their degree programs is considerable at TCUs. There is a broad need for basic adult educational programs and TCUs need adequate funding to support these essential activities. *TCUs respectfully request that the Subcommittee direct \$5.0 million of the Adult Education State Grants appropriated funds to make awards to TCUs to help meet the ever increasing demand for basic adult education and remediation program services that exists on their respective reservations.*

**American Indian Teacher/Administrator Corps (Special Programs for Indian Children):** American Indians are severely underrepresented in the teaching and school administrator ranks nationally. These competitive programs are designed to produce new American Indian teachers and school administrators for schools serving American Indian students. These grants support recruitment, training, and in-service professional development programs for Indians to become

effective teachers and school administrators and in doing so become excellent role models for Indian children. We believe that the TCUs are ideal catalysts for these two initiatives because of their current work in this area and the existing articulation agreements they hold with 4-year degree awarding institutions. *The TCUs request that the Subcommittee support these two programs at \$10.0 million and \$5.0 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.*

**DEPARTMENT OF HEALTH AND HUMAN SERVICES/ADMINISTRATION FOR CHILDREN AND FAMILIES/HEAD START**

**Tribal Colleges and Universities (TCU) Head Start Partnership Program:** The TCU-Head Start Partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. Graduates of these programs help meet the degree mandate for all Head Start program teachers. More importantly, this program has afforded American Indian children Head Start programs of the highest quality. A clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funds made available for the TCU-Head Start Partnership. In FY 1999, the first year of the program, some colleges were awarded 3-year grants, others 5-year grants. In FY 2002, no new grants were awarded. In FY 2003, funding for eight new TCU grants was made available, but in FY 2004, only two new awards could be made because of the lack of adequate funds. The President's February 26, 2009 budget summary includes an additional \$1.0 billion to improve and expand Head Start. *The TCUs request that the Subcommittee direct the Head Start Bureau to designate a minimum of \$5.0 million, of the over \$8.0 billion included in the budget summary, for the TCU-Head Start Partnership program, to ensure that this critical program can continue and expand so that all TCUs have the opportunity to participate in the TCU- Head Start Partnership program.*

**Conclusion**

Tribal Colleges and Universities are providing access to higher education opportunities to many thousands of American Indians and essential community services and programs to many more. The modest Federal investment in TCUs has already paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. TCUs need your help if they are to sustain and grow their programs and achieve their missions to serve their students and communities.

Thank you again for this opportunity to present our funding recommendations. We respectfully ask the Members of the Subcommittee for their continued support of the nation's Tribal Colleges and Universities and full consideration of our FY 2010 appropriations needs and recommendations.

Official Testimony for the Record  
For the Subcommittee on Labor, Health and Human Services and Education  
Committee on Appropriations  
United States House of Representatives  
Washington, DC

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**Madam Chairman and Members of the Subcommittee:**

The American Institute for Medical and Biological Engineering (AIMBE) appreciates the opportunity to submit testimony to advocate for funding for research within the National Institutes of Health (NIH) broadly, and specifically research funding within the National Institute for Biomedical Imaging and Bioengineering (NIBIB). NIH and NIBIB provide avenues for research funding that are vital to the nation's efforts in medical and biological engineering (MBE) innovation. AIMBE represents 50,000 individuals and organizations throughout the U.S., including major healthcare companies, academic research institutions and high-level engineers, scientists and clinicians whose research and developments have touched the lives and health of most all Americans. While today's testimony focuses in the impact MBE has on improving the healthcare of Americans, it is important to note that MBE can also have a positive impact on many of the other important issues facing us today; ranging from improvements to the environment, to finding green-energy solutions, to solving problems relating to hunger, disease prevention and economic growth. As advocates for MBE, AIMBE was founded in 1991 to establish a clear and comprehensive identity for the field of medical and biological engineering - which applies principles of engineering science and practice to imagine, create, and perfect medical and biological technologies that are used to improve the health and quality of life of Americans and people across the world.

AIMBE applauds the support of this committee in the past to provide funding to NIH, and we were particularly pleased to see a strong investment in NIH research which came from the American Recovery and Reinvestment Act. However, we believe more stable, adequate and reliable funding is necessary to further ensure America remains competitive. We therefore support the following recommendations:

- 1) AIMBE supports funding the NIBIB at the level of \$500M for FY 2010. While a significant increase from the \$300M budget for FY 2009, this proposed FY 2010 funding level would bring funding back in-line with the original 5-year funding Congressional budget estimate for NIBIB which was produced in 2004. This increase in funding would help to support

important high-risk, high-reward research being performed in the NIBIB Quantum grant program, for example. The research being conducted under the Quantum grant program is the very definition of high-risk, high-reward research and has the potential to be a catalyst for innovation with the MBE community.

- 2) Within NIH, AIMBE supports the development of a Proof of Concept (POC) Block Grant program, in which NIH would choose select universities to act as POC centers, helping to foster collaboration between industry, government and academia. These grants, funded at a maximum of \$1 million per grant, would allow local universities to work with local industry and utilize a peer-review processes to identify results of engineering research that have commercialization potential.
- 3) Finally, AIMBE encourages strong collaboration between Federal agencies, and the private sector, so that engineering research can translate to innovations. Medical and biological engineering is by its nature an interdisciplinary field, drawing on experts from basic research to areas ranging from biomechanics to computational biology to electrical engineering to chemists to areas known directly as bio- or biomedical engineering. This interdisciplinary approach to solving quality of life issues should be echoed in the government through inter-agency collaboration. Opportunities exist for inter-agency collaboration and public-private partnerships to build on public and private sector resources to work together to solve issues threatening the quality of life for Americans and people across the globe. In many instances, without such partnerships, research would be too costly for the parties to conduct individually, proving costly to the health and wellbeing of Americans.

#### **NIBIB as an Innovation Stimulus**

While each Institute within the NIH plays a vital role in researching and identify disease prevention and treatments positively impacting patient outcomes; one Institute within NIH plays a unique role and has not benefited from large-scale NIH funding increases, such as the doubling of the budget in 2004. First appropriated in 2002, the mission of NIBIB is to improve health by leading the development and accelerating the application of biomedical technologies. The Institute is committed to integrating the physical and engineering sciences with the life sciences to advance basic research and medical care. This is achieved through: research and development of new biomedical imaging and bioengineering techniques and devices to fundamentally improve the detection, treatment, and prevention of disease; enhancing existing imaging and bioengineering modalities; supporting related research in the physical and mathematical sciences; encouraging research and development in multidisciplinary areas; supporting studies to assess the effectiveness and outcomes of new biologics, materials, processes, devices, and procedures; developing technologies for early disease detection and assessment of health status; and developing advanced imaging and engineering techniques for conducting biomedical research at multiple scales. Further, NIBIB plays a unique role within NIH as one of the few Institutes that fosters a research relationship with academia, industry and the government. Finally, the NIBIB plays an important role in providing engineering research resources to the entirety of the NIH.

The FY2009 NIBIB Budget submission is \$300.2 million, represented a 1.2% decrease from the FY2008 appropriation, and is 40.4% lower then the original five-year Congressional budget

estimate for NIBIB funding of \$504 million. An existing program that can have a measurable impact on improving the quality of life of citizens is the NIBIB Quantum Grant program. The research being conducted under the Quantum Grant program is the very definition of high-risk, high-reward research. As the economy worsens, private industry and private investors are less likely to invest in high risk research, potentially slowing the pace of innovation. By investing in bioengineering research, NIBIB is helping to fill the void of research and development funding which could lead to the development of cutting edge technologies that providing a bridge from scientific principle to patient care. Further, research conducted under the Quantum Grants program has the potential to be highly implementable and may help to reduce the cost of healthcare in this country.

The Quantum Grants program challenges the research community to propose projects that have a highly focused, collaborative, and interdisciplinary approach to solve a major medical problem or to resolve a highly prevalent technology-based medical challenge. The program consists of a three-year exploratory phase to assess feasibility and identify best approaches, followed by a second phase of five to seven years. Major advances in medicine leading to quantifiable improvements in public health require the kind of funding commitment and intellectual focus found in the Quantum Grants program at NIBIB.

The five Quantum Grants currently funded focus on stem cell therapies for diabetes and stroke, nanoparticles to help eliminate brain tumors, development of an implantable device to replace kidney dialysis, and a microchip to capture circulating tumor cells for clinical and research purposes. All these areas of research have, in their early stages of funding, shown much promise in the laboratory setting. An increase of funding to NIBIB and the Quantum Grants program may offer opportunities to expedite research beyond laboratory study and into clinical trial.

The fields of biomedical imaging and bioengineering are expanding rapidly, from the diagnosis, and treatment of diseases and disabilities to the analysis of structure and function at the genetic level. Research objectives such as the Quantum Grants programs enable NIBIB to accelerate discoveries and create and capitalize on opportunities to profoundly improve healthcare.

#### **The Fundamental Role of Engineering Research**

Advances in the process of engineering research, in a variety of fields, are a part of technological innovation. Medical and biological engineering draws from research specialties across disciplines, bringing together innovative teams that create unique solutions to the most pressing health problems. Commonly, the basic science necessary for problem solving is available at the onset of research. Engineering research looks to solve problems in, quality of life for example, through applying the basic scientific principals to a multi-disciplinary research approach. For example, the insulin pump is the result of multi-disciplinary effort for better management of diabetes which reduces serious and costly side effects such as cardiovascular disease, stroke, liver and kidney damage, and neuropathy. These pumps enable many diabetic patients to live more normal lives as productive members of society. As a result, there are fewer absences from work and reduced health care and hospital costs. The science to develop an insulin pump existed well before the creation of the medical device; however it took engineering research to apply the basic science toward product development.

A similar advancement through MBE is the use of angioplasty with an arterial stent which releases drugs directly to the coronary artery. This advancement has replaced more than 500,000 bypass surgeries a year, at an annual cost savings of \$4 billion, and an immeasurable improvement in the quality of life of patients receiving this treatment.

Engineering research in human physiology, specifically in range of motion and function, has increased the function for artificial limbs. The decreasing mortality and increasing number of disabled war veterans highlights the need for more highly functional prosthetics. Engineering research and development processes have taken the strapped wooden leg to a realistic synergic leg and foot transtibial prosthetic that employs advanced biomechanics and microelectronic controls to allow a fuller range of motion, including running. Basic engineering research in polymers and materials science has changed the feel and look of prosthetic limbs so they are no longer easily discernable, reducing the stigma, and making them more durable, reducing the cost of maintenance and replacement.

The engineering research process has played a large part in extending and deploying innovative imaging technologies such as magnetic resonance imaging (MRI) and ultra-fast computerized tomography (CT scan). These technologies facilitate early detection of disease and dysfunction, allowing for earlier treatment and slowing the progression of disease. Innovative diagnostics such as these reduce the acute costs of healthcare.

The nation deserves to obtain a strong return on its investment in the basic medical research funded by NIH. Additional engineering research, including translation to new devices and efficient medical processes, is a critical part of obtaining that return. Our citizens and the societies of the world obtain benefits as that return is realized. The combination of basic scientific studies and engineering research, will in turn, lead to many technological innovations. Industry will supply developmental engineering research; however, they usually spurn the fundamental level of engineering research done at NIH due to the high risks that moneys invested will not be returned in a short period. The government needs to continue to fund the vital research at NIH to continue to be a leader in the global arena, leading to innovative product growth and creating new jobs.

#### **Emphasizing Collaboration between Agencies**

In the last few decades, the advancements and promises born from the information age have brought incredible changes to our lives. When presented with new opportunities for advancement, we as a society have a tendency to be resistant, to stick with the old way out of force of habit or fear of the unknown. Other times, we are prevented from realizing the full potential that change is able to bring us, because of an inability to accept new advancements uniformly. In either case, the end-result is the same: we do not receive the full benefit from the change which we either adopt or implement.

AIMBE is currently working to plan a summit meeting titled, "Interoperability Summit: Establishing the Infrastructure for Health Assurance and Disease Prevention," to present a set of scientific policy recommendations to the President of the United States and the administration, focusing on how the United States health care delivery system could and should be transformed rather than merely reformed by encouraging increased collaboration between federal agencies

that have some impact on health and quality of life issues. Today's example of the health crisis caused by "swine flu" is an example where greater inter-agency collaboration; with a more accessible information flow, might have permitted the wisdom to percolate to the top more quickly and certainly. The fact remains that multiple administrations and numerous proposed reforms of the U.S. health care enterprise have had limited success. We are at a time when the need is for definite, strong forward progress. Toward that progress, we note that the American scientific and engineering communities have never had a collective and measurable hand in contributing to and improving upon the American health care enterprise. While the AIMBE is spearheading the Summit, the aim is to invite relevant scientific organizations that have the wealth of knowledge and experience in order to generate forward high-level recommendations to Congress and the Administration.

AIMBE looks forward to the opportunity to continue this dialogue with you all individually. Any questions or requests for further information should be provided to Benjamin Corb, AIMBE's Director of Public Affairs. Requests can be made electronically to [bcorb@aimbe.org](mailto:bcorb@aimbe.org), or via telephone at 202.496.9660.

STATEMENT  
OF  
THE AMERICAN LIVER FOUNDATION

PRESENTED  
TO  
THE UNITED STATES HOUSE OF REPRESENTATIVES  
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES

BY  
ALLAN WOLKOFF, M.D.  
CHAIRMAN OF THE BOARD

WASHINGTON, D.C.

May 1, 2009



Mr. Chairman and Members of the Subcommittee, thank you for giving the American Liver Foundation the opportunity to provide testimony as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2010. My name is Dr. Allan Wolkoff and I am the Chairman of the Board of Directors of the American Liver Foundation (ALF), a national voluntary health organization dedicated to the prevention, treatment and cure of hepatitis and other liver diseases through research, education and advocacy. I am also a Professor of Medicine and Chief of the Division of Hepatology at the Albert Einstein College of Medicine.

ALF has 25 Chapters nationwide and provides information to 300,000 patients and families. Over 70,000 physicians, including primary care practitioners and liver specialists and scientists also receive information from ALF. The ALF Board of Directors is composed of scientists, clinicians, patients and others who are directly affected by liver diseases. Every year ALF handles over 100,000 requests for information, helping patients and their families understand their illnesses, informing them about available services, and showing them that there are knowledgeable and concerned individuals to assist them in every possible way.

Mr. Chairman, ALF joins the Ad Hoc Group for Medical Research Funding, a coalition of some 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending at least a 7% increase for the National Institutes of Health in FY 2010. While the ALF recognizes the demands on our nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify increased funding levels for the NIH. To ensure that NIH's momentum is not further eroded, and to ensure the fight against diseases and disabilities that affect millions of Americans can continue, ALF supports a minimum increase of 7% for the NIH in FY 2010 and a minimum increase of a 7% for the National Institute for Diabetes and Digestive and Kidney Diseases and for liver disease research across all NIH Institutes.

In addition to the NIH, there are a number of programs within the jurisdiction of the subcommittee that are important to ALF including the Centers for Disease Control's Division of Viral Hepatitis and HRSA's Division of Transplantation. Mr. Chairman, our specific recommendations for these and other areas of interest are summarized in a table at the end of this statement.

#### RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, ALF appreciates your leadership and the leadership of this Subcommittee in supporting NIH in a time of fiscal austerity. Your leadership in supporting CDC and HRSA's Division of Transplantation are also greatly recognized and appreciated. These programs are important to our shared goals of improving the public health response to the threats of hepatitis and liver disease and to increasing the rate of organ donation. We applaud the Committee's leadership in making progress in these important areas and to allocating increased funding to these programs during periods of fiscal austerity.

#### RECOGNIZING THE LEADERSHIP OF THE NIH

Mr. Chairman, I would also like to take this opportunity to commend the leadership of NIH, and especially the leadership of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for their strong support of liver disease research. In the summer of 2002, a member of this Subcommittee, Congressman Dan Miller, introduced a piece of legislation titled the Liver Disease Research Enhancement Act. The legislation, reintroduced in the 111<sup>th</sup> Congress by Congressmen Stephen Lynch and Peter King, was introduced after several months of deliberation and consultation with the leadership of NIH, with the intention of creating a center within NIDDK focused solely on liver and liver-related diseases. This bill will streamline the study and funding of liver disease research by creating a Liver Disease Research Advisory Board that will include preeminent scientists at the NIH, and from across the country to develop a Liver Disease Research Action Plan to guide future NIH funding decisions and help the liver research community prioritize research efforts. In addition the bill provides new authorities necessary to help insure that the scientific opportunities identified by the Liver Disease Research Action Plan are adequately funded.

After the bill was first introduced, the NIH independently implemented many of the provisions of this legislation, including the establishment of a Liver Disease Branch and the creation of a Liver Disease Research Action Plan, which the NIH continues to update each year. The Research Action Plan is an important blueprint for the future of liver disease research; however, ALF is concerned that without the authorities included in the legislation, implementation of the plan will proceed slowly. We recommend the Liver Research Enhancement Act to the Subcommittee as necessary steps needed to improve the rate of scientific discovery thus leading to cures and better treatment for liver disease.

#### FUNDING THE LIVER DISEASE RESEARCH ACTION PLAN

Mr. Chairman, in December of 2004, the NIDDK released the Liver Disease Research Action Plan outlining major research goals for the various aspects of liver disease. Working with the leading scientific experts in the field, the plan is organized into 16 chapters and identifies numerous areas of research important to virtually every aspect of liver disease, including: improving the success rate of therapy of hepatitis C; developing noninvasive ways to measure liver fibrosis; developing sensitive and specific means of screening individuals at high risk for early hepatocellular carcinoma; developing standardized and objective diagnostic criteria for major liver diseases and their grading and staging; and decreasing the mortality rate from liver disease. Each year, the plan is reviewed and updated. The ALF urges the Committee to provide adequate funding and policy guidance to NIH to urge continued implementation of the plan.

#### CDC'S DIVISION OF VIRAL HEPATITIS

The Division of Viral Hepatitis (DVH) is included in the National Center for HIV/AIDS, Viral

Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis, a disease which impacts over 6 million Americans and often leads to liver cancer and liver failure. The DVH provides the scientific and programmatic foundation for the prevention, control and elimination of hepatitis virus infections in the U.S. and also assists the international public health community in these activities. DVH works with state and local health departments to provide the guidance and technical expertise needed to integrate hepatitis prevention services such as hepatitis A and B vaccine, hepatitis B and C counseling, and testing and referral to existing public health programs serving individuals at high risk.

The Division of Viral Hepatitis currently funded at \$17.5 million would need an annual funding level of at least \$40 million to restore its funding level, adjusted for inflation, to the funding level it received in FY 2003. The American Liver Foundation urges a FY 2010 funding level for the Division of Viral Hepatitis of \$40 million.

#### INCREASING THE SUPPLY OF ORGANS FOR DONATION

As the Subcommittee knows, even with advances in the use of living liver donors, the increase in the demand for livers needed for transplantation will continue to exceed the number available. The need to increase the rate of organ donation is critical. Each day approximately 79 people receive an organ transplant, but another 12 people die because organ demand far outweighs the supply and the gap continues to widen. For example, in 2007, while 6,318 liver transplants were performed, there were over 16,400 individuals on the list waiting for liver transplantations and about 1,493 people died due to the lack of a donor liver.

Recognizing the importance of this issue, Congress passed, and the President signed, the Organ Donation and Recovery Improvement Act of 2004 (P.L. 108-216) authorizing an increase of \$25 million for organ donation activities in the first year, and such sums as necessary in following years, and yet, it was only last year that additional funding of \$1 million has been provided to implement this legislation. To address these needs, ALF recommends that the Division of Transplantation receive a \$10 million increase in FY 2010, an increase consistent with an amendment adopted by the Senate when it passed the FY 2010 Budget Resolution on April 2, 2010.

#### SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for its past leadership. Significant progress has been made in developing better treatments and cures for the diseases that affects mankind due to your leadership and the leadership of your colleagues on this subcommittee. Significant progress has also similarly been made in the fight against liver disease. For FY 2010 we recommend a 7%, increase for NIH above the level of the FY 2009 funding levels, with the level of liver disease research also increased by at least 7%. We also urge a \$40 million for the CDC's Division of Viral Hepatitis to strengthen the public health response to hepatitis and liver disease and a \$10 million increase to HRSA's Division of Transplantation necessary to increase

the rate of organ donation. Mr. Chairman, if this country is to maintain its leadership role in health maintenance, disease prevention, and the curing of diseases, adequate funding for NIH, CDC and HRSA is paramount. The ALF appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

ALF RECOMMENDATIONS FOR FISCAL YEAR 2010 FUNDING

NIH and the Liver Disease Research Action Plan

- 7% increase for NIH overall and 7% for the National Institute of Diabetes and Digestive and Kidney Diseases;
- +\$25 million to implement the Liver Research Action Plan

CDC: National Hepatitis C Prevention Strategy, Public Health Information, HAV & HBV Vaccinations

- Fund the CDC's Division of Viral Hepatitis at \$40 million to strengthen the public health response to chronic viral hepatitis; and

HRSA: Expanding the supply of organs

- + \$10 million for the Organ Transplantation Program at HRSA.

**TESTIMONY OF  
DAVID MELTZER, SENIOR VICE PRESIDENT, INTERNATIONAL SERVICES  
THE AMERICAN NATIONAL RED CROSS  
(MeltzerD@usa.redcross.org (202) 303-4271)**

**AND ON BEHALF OF  
THE HONORABLE TIMOTHY E. WIRTH, PRESIDENT,  
UNITED NATIONS FOUNDATION  
(TWirth@unfoundation.org, (202) 887-9040)**

**IN SUPPORT OF FUNDING FOR THE CENTERS FOR DISEASE CONTROL AND  
PREVENTION (CDC)**

**APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**U.S. HOUSE OF REPRESENTATIVES  
May 1, 2009**

Chairman David Obey, Ranking Member Todd Tiahrt, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles control.

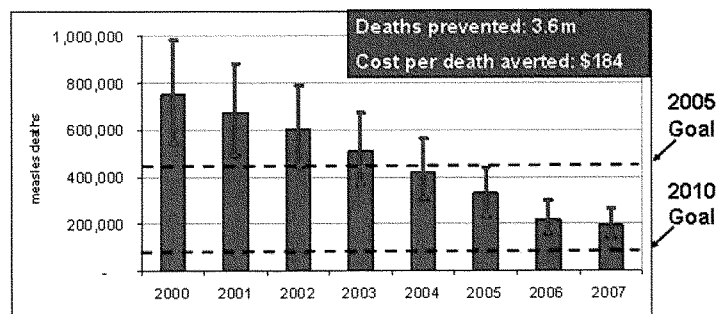
In 2001, CDC – along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF – became one of the spearheading partners of the Measles Initiative, a partnership committed to reducing measles deaths globally. The current UN goal is to reduce measles deaths by 90% by 2010 compared to 2000 estimates. The Measles Initiative is committed to reaching this goal by providing technical and financial support to governments and communities worldwide.

The Measles Initiative has achieved “spectacular”<sup>1</sup> results by supporting the vaccination of more than 600 million children. Largely due to the Measles Initiative, global measles mortality dropped 74%, from an estimated 750,000 deaths in 2000 to 197,000 in 2007. During this same period, measles deaths in Africa fell by 89%, from 395,000 to 45,000.

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<sup>1</sup> The Lancet, Volume 8, page 13 (January 2008).

### Estimated Measles Deaths, 2000-2007



High-low lines indicate uncertainty bounds  
Source: WHO/IVB, November 2008

Working closely with host governments, the Measles Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$670 million and provided technical support in more than 60 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2007, an estimated 3.6 million measles deaths were averted as a result of accelerated measles control activities (increased routine immunization coverage and mass immunization campaigns) at a donor cost of \$184/death averted, making measles mortality reduction one of the most cost-effective public health interventions.

Nearly all the measles vaccination campaigns have been able to reach more than 90% of their target populations. Countries recognize the opportunities that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, Vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine, and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. The scale of these distributions is immense. For example, more than 37 million ITNs were distributed in vaccination campaigns in the last few years. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

Countries are well positioned to achieve the 2010 goal and to take a bold step toward achievement of the 2015 Millennium Development Goal #4 of reducing under-five child mortality. However, achieving the 2010 goal will require:

- Accelerating activities, both campaigns and further efforts to improve routine measles coverage, in India since it is the greatest contributor to the global burden of measles.
- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90% of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality follow-up campaigns.
- Securing sufficient funding for measles-control activities both globally and nationally. The Measles Initiative faces a funding shortfall of an estimated US \$100 million for 2010. Implementation of timely follow-up campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at global level to support activities to reduce measles mortality makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 90%.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles cases in other countries, U.S. children are also being protected from the disease. Measles can cause severe complications and death. A major resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been strengthened and endemic transmission of measles cases have been eliminated here since 2000. However, importations of measles cases into this country continue to occur each year. In 2008, the number of reported measles cases in the United States more than doubled and outbreaks are currently ongoing in Virginia, Maryland, Washington DC, Pennsylvania, California and Missouri. These outbreaks cause needless suffering and accrue public health costs which in the United States are upwards of \$150,000 to respond to each case.

#### **The Role of CDC in Global Measles Mortality Reduction**

Since FY 2001, Congress has provided approximately \$42 million annually in funding to CDC for global measles control activities. These funds were used toward the purchase of approximately 415 million doses of measles vaccine for use in large-scale measles vaccination campaigns in more than 60 countries in Africa and Asia, and for the provision of technical support to Ministries of Health in those countries. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and

- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels.

While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles Initiative, there is no doubt that CDC's support – made possible by the funding appropriated by Congress – was essential in helping achieve the sharp reduction in measles deaths in just seven years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles Initiative is fortunate in having a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In FY 2009, Congress has appropriated approximately \$41.8 million to fund CDC for global measles control activities. The American Red Cross and the United Nations Foundation thank Congress for the financial support that has been provided to CDC in the past and this year. We respectfully request a total of \$51.8 million for FY 2010 funding for CDC's measles control activities so that the gains made to date can continue and the 2010 goal of a 90% reduction in measles deaths can be achieved.

The additional funds we are seeking for CDC are critical for:

- Sustaining the great progress in measles mortality reduction in Africa by strengthening measles surveillance and strengthening the delivery of measles vaccine through routine immunization services to protect new birth cohorts;
- Conducting large-scale measles vaccination campaigns in South Asia, especially in India, thus protecting millions of children;

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.





**Statement  
of the  
American Nurses Association  
to the  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives**

***FY 2010 Funding for Nursing Workforce Development Programs  
and the National Institute for Nursing Research***

**April 28, 2009**

Submitted by:  
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The American Nurses Association (ANA) appreciates this opportunity to comment on Fiscal Year (FY) 2010 appropriations for nursing education, workforce development, and research programs. Founded in 1896, ANA is the only full-service national association representing registered nurses (RNs). Through our 51 constituent member associations, ANA represents RNs across the nation in all practice settings.

The ANA gratefully acknowledges this Subcommittee's history of support for nursing education and research. We appreciate your continued recognition of the important role nurses play in the delivery of quality health care services. This testimony will give you an update on the status of the nursing shortage, its impact on the nation, and the outlook for the future.

**The Nursing Shortage Today**

The nursing shortage is far from solved. Here are a few quick facts:

- The American Hospital Association reported that hospitals needed 116,000 more RNs to fill immediate vacancies in July, 2007. Hospitals report that this vacancy rate is hampering the ability to provide emergency care.
- The Bureau of Labor Statistics reports that registered nursing will have remarkable job growth in the time period spanning 2006 – 2016. During this time decade, the health care system will require more than 1 million new nurses.
- The Health Resources and Services Administration (HRSA) projects that the supply of

nurses in America will fall 26 percent (more than 1 million nurses) below requirements by the year 2020. In year 2020, Wisconsin's demand for full-time RNs will outstrip the supply by 20 percent (a shortage of 10,200 RNs). New York's shortage will reach 39 percent (54,200 RNs) and Ohio will have a 30 percent shortage (34,000 RNs). California's demand will outstrip its supply by 45 percent (116,600 RNs).

This growing nursing shortage is having a detrimental impact on the entire health care system. Numerous studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the January/February 2006 issue of *Health Affairs* showed that hospitals could avoid 6,700 deaths per year by increasing the amount of RN care provided to their patients. This study, "Nurse Staffing in Hospitals: Is There a Business Case for Quality?" by Jack Needleman, Peter Buerhaus, et al. also revealed that hospitals are currently providing four million days worth of inpatient care annually to treat avoidable patient complications associated with a shortage of RN care.

Research published in the October 23, 2002 *Journal of the American Medical Association* also demonstrated that more nurses at the bedside could save thousands of patient lives each year. In reviewing more than 232,000 surgical patients at 168 hospitals, researchers from the University of Pennsylvania concluded that a patient's overall risk of death rose roughly 7 percent for each additional patient above four added to a nurse's workload.

A Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) study published in 2002 shows that the shortage of nurses contributes to nearly a quarter of all unexpected incidents that kill or injure hospitalized patients.

#### **Nursing Workforce Development Programs**

Federal support for the Nursing Workforce Development Programs contained in Title VIII of the Public Health Service Act is unduplicated and essential. The 107<sup>th</sup> Congress recognized the detrimental impact of the developing nursing shortage and passed the Nurse Reinvestment Act (PL 107-205). This law improved the Title VIII Nursing Workforce Development programs to meet the unique characteristics of today's shortage. This achievement holds the promise of recruiting new nurses into the profession, promoting career advancement within nursing, and improving patient care delivery. However, this promise cannot be met without a significant investment. **ANA strongly urges you to increase funding for Title VIII programs by at least \$44 million to a total of \$215 million in FY 2010.** This funding amount has been supported by a bipartisan group of 136 Representatives in a Dear Colleague letter recently sent to this Subcommittee.

Current funding levels are clearly failing to meet the need. In fiscal year 2008, the Health Resources and Services Administration (HRSA) was forced to turn away 92.8% of the eligible applicants for the Nurse Education Loan Repayment Program (NELRP), and 53% of the eligible applicants for the Nursing Scholarship program due to a lack of adequate funding. These programs are used to direct RNs into areas with the greatest need – including departments of public health, community health centers, and disproportionate share hospitals.

In 1973, Congress appropriated \$160.61 million to Title VIII programs. Inflated to today's dollars, this appropriation would equal \$763.52 million, more than four times the FY 2009 appropriation. Certainly, today's shortage is more dire and systemic than that of the 1970's; it deserves an equivalent response.

Title VIII includes the following program areas:

**Nursing Education Loan Repayment Program & Scholarships:** This line item is comprised of the Nurse Education Loan Repayment Program (NELRP) and the Nursing Scholarship Program (NSP). In FY 2009, the Nurse Education Loan Repayment Program and Scholarships received \$37 million.

The NELRP repays up to 85 percent of a RN's student loans in return for full-time practice in a facility with a critical nursing shortage. The NELRP nurse is required to work for at least two years in a designated facility, during which time the NELRP repays 60 percent of the RN's student loan balance. If the nurse applies and is accepted for an optional third year, an additional 25 percent of the loan is repaid.

The NELRP boasts a proven track record of delivering nurses to facilities hardest hit by the nursing shortage. HRSA has given NELRP funding preference to RNs who work in departments of public health, disproportionate share hospitals, skilled nursing facilities, and federally-designated health centers. However, lack of funding has hindered the full implementation of this program. In FY 2008, 92.8 percent of applicants willing to immediately begin practicing in facilities hardest hit by the shortage were turned away from this program due to lack of funding.

The NSP offers funds to nursing students who, upon graduation, agree to work for at least two years in a health care facility with a critical shortage of nurses. Preference is given to students with the greatest financial need. Like the loan repayment program, the NSP has been stunted by a lack of funding. In FY 2008, HRSA received 3,039 applications for the nursing scholarship. Due to lack of funding, a mere 177 scholarships were awarded. Therefore, 2,862 nursing students (94 percent) willing to work in facilities with a critical shortage were denied access to this program.

**Nurse Faculty Loan Program:** This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may use these funds to pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a four-year period. In FY 2009, this program received \$11.5 million.

This program is vital given the critical shortage of nursing faculty. America's schools of nursing can not increase their capacity without an influx of new teaching staff. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In FY 2008, HRSA funded 95 faculty loans.

**Nurse Education, Practice, and Retention Grants:** This section is comprised of many programs designed to support entry-level nursing education and to enhance nursing practice. All

together, the Nurse Education, Practice, and Retention Grants received \$37.3 million in FY 2009.

The education grants are designed to expand enrollments in baccalaureate nursing programs; develop internship and residency programs to enhance mentoring and specialty training, and; provide new technologies in education including distance learning.

Retention grant areas include career ladders and improved patient care delivery systems. The career ladders program supports education programs that assist individuals in obtaining the educational foundation required to enter the profession, and to promote career advancement within nursing. Enhancing patient care delivery system grants are designed to improve the nursing work environment. These grants help facilities to enhance collaboration and communication among nurses and other health care professionals, and to promote nurse involvement in the organizational and clinical decision-making processes of a health care facility. These best practices for nurse administration have been identified by the American Nurse Credentialing Center's Magnet Recognition Program®. These practices have been shown to double nurse retention rates, increase nurse satisfaction, and improve patient care.

**Nursing Workforce Diversity:** This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds - including racial and ethnic minorities, as well as individuals who are economically disadvantaged. In FY 2008, 85 applications were received for workforce diversity grants, 51 were funded. In FY 2009, these programs received \$16 million.

**Advanced Nurse Education:** Advanced practice registered nurses (APRNs) are nurses who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, psychiatry, midwifery, neonatology, and women's & adult health. Title VIII grants have supported the development of virtually all initial state and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas. In FY 2008, 7,650 advanced education nurses were supported through these programs. In FY 2009, these programs received \$64.4 million.

These grants also provide traineeships for masters and doctoral students. Title VIII funds more than 60 percent of U.S. nurse practitioner education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of the nurse anesthesia graduates supported by this program go on to practice in medically underserved communities. A study published last year in the *Journal of Rural Health* showed that 80% of the nurse practitioners who attended a program supported by Title VIII chose to work in a medically underserved or health profession shortage area after graduation.

**Comprehensive Geriatric Education Grants:** This authority awards grants to train and educate nurses in providing health care to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train

faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. In FY 2009, these grants received 4.5 million.

The growing number of elderly Americans and the impending health care needs of the baby boom generation make this program critically important. In FY 2006, HRSA continued 8 previously awarded grants and awarded 11 new ones.

#### **NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)**

ANA also urges the Subcommittee to increase funding for the NINR, one of the institutes at the National Institutes of Health (NIH). The Institute's research focus transcends disciplines to address issues of health management, symptom management, and caregiving; health promotion and disease prevention; end-of-life care; technology integration; and research capacity development. This research is integral to improving the effectiveness of nursing care. Advances in nursing care arising from behavioral and biomedical research have shown excellent progress in reducing health care costs. Research programs supported by NINR address a number of critical public health and patient care questions. The cross-discipline research is driven by real and immediate problems currently facing patients and their families.

Recent NINR funded studies have shown that inadequate nurse staffing increases risks for patients; coping skills training improves teens' self-management of diabetes; a health care team helps reduce high blood pressure among inner-city black men; a community-based program improves self-management of arthritis among older Hispanics; home nursing visits benefit low-income mothers and their children; and transitional care improves outcomes for elders after leaving the hospital. NINR is leading the NIH research on end-of-life and palliative care. NINR is also the lowest funded institute at NIH. In FY 2009, NINR received \$141.88 million. ANA recommends \$178 million, or a 25% increase over FY 2009, in FY 2010 NINR funding.

#### **CONCLUSION**

While ANA appreciates the continued support of this Subcommittee, we are concerned that Title VIII funding levels have not been sufficient to address the growing nursing shortage. The nursing shortage will continue to worsen if significant investments are not made. Recent efforts have shown that aggressive and innovative recruitment efforts can help avert the impending nursing shortage – if they are adequately funded.

ANA asks you to meet today's shortage with a relatively modest investment of \$215 million in Title VIII programs. Additionally, an investment of \$178 million in the NINR will help assure that nurses are equipped with the latest information and research needed to provide the best patient care possible.

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*This statement is submitted to the House Appropriations Subcommittee on Labor-HHS, and Education.*

## **The American Physiological Society Statement on FY 2010 Funding for the National Institutes of Health**

The American Physiological Society (APS) thanks the Chairman and all the Members of this Subcommittee for their support for the National Institutes of Health (NIH). The funds you included in the American Recovery and Reinvestment Act of 2009 (ARRA) are providing the NIH with a substantial influx of resources at a crucial time. Several consecutive years of stagnant budget growth had been eroding the scientific capacity painstakingly built up during the doubling. The rapid distribution of ARRA funds will allow scientists to explore new avenues of promising research through the funding of additional grants, which is already building momentum and sparking excitement in the research community. The stimulus funds represent a first step toward enabling NIH to maintain and to increase employment for highly skilled workers, purchase critical equipment and supplies, and enhance research capacity at institutions across the country. However, consistent future budget growth for NIH will be necessary to sustain this momentum beyond the period of stimulus spending and prevent an abrupt halt in these new research initiatives after the ARRA. Furthermore, absent a continued increase in support for NIH, as many as 20,000 jobs created in the biomedical sciences by the stimulus money could be lost. **Therefore the APS urges you to make every effort to provide the NIH with a 7% increase in FY 2010.**

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has nearly 10,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S. The APS offers these comments on the budget recognizing both the enormous financial challenges facing our nation and the great opportunity before us to make progress against disease.

As a result of improved health care, Americans are living longer and healthier lives in the 21<sup>st</sup> century than ever before. However, diseases such as heart failure, diabetes, cancer and emerging infectious diseases such as the swine flu continue to inflict a heavy burden on our population. The NIH invests heavily in basic research to explore the mechanisms

and processes of disease. This investment will result in new tools and knowledge that can be used to design novel treatments and prevention strategies.

The NIH selects and funds investigator-initiated research of only the highest scientific merit through the use of the peer review system. Among the breakthroughs in the last year:

- NIH-funded researchers discovered that people with certain genetic variants are at increased risk for a stroke. This genetic link provides molecular clues to how strokes develop and also moves the field closer to personalized medicine. This work was performed by researchers who collaborated to study large populations of patients over a long period of time, and is an example of research that was supported by multiple institutes within the NIH.<sup>1</sup>
- Scientists recently discovered that adults retain brown fat, a metabolically active type of fat tissue that was previously thought to exist only in infants and children. Because brown fat burns calories and energy, there is hope that this discovery could lead to new treatments for obesity and diabetes.<sup>2</sup>
- Researchers studying obesity and diet in an animal model found that chronic consumption of high levels of fructose leads to excess weight gain and molecular changes when paired with a high-fat, high-calorie diet. Understanding the physiological changes associated with the development of obesity is a first step toward the design of interventions that could prevent the serious health consequences associated with being overweight.<sup>3</sup>

Over the past several years, the Office of the Director has supplemented existing research programs with new types of awards as part of the NIH Roadmap for Medical Research. These include the New Innovator, Pioneer and Transformative Research Award Programs. Such programs support bold and creative researchers as they engage in high-risk, high-reward research, thus allowing more flexibility to explore novel ideas and challenge existing paradigms. The NIH is also using these programs as a model for distributing funds under the ARRA. The Research and Research Infrastructure "Grand Opportunities" program will fund potentially high-impact areas of science that will benefit from short term funding.

The NIH is also home to the Institutional Development Award (IDeA) Program. Established in 1993, the goal of the IDeA program is to broaden the geographic distribution of NIH funds by serving researchers and institutions in areas that have not historically received significant NIH funding. IDeA builds research capacity and improves competitiveness in those states through the development of shared resources, infrastructure and expertise. IDeA currently serves institutions and investigators in 23 states and Puerto Rico.

In addition to supporting research, the NIH must also address workforce issues to ensure that our nation's researchers are ready to meet the challenges they will face in the future. Recent data from the NIH shows that the average age of NIH supported principal investigators is now 50.8 years.<sup>4</sup> This is up nearly 12 years from the average principal

investigator's age of 39.1 years in 1980. In addition, the average age at which a researcher obtains their first major research award from NIH has increased to 42.4 years. As the scientific workforce continues to age, and more researchers retire, there may be an insufficient number of young scientists who are trained to replace them. Over the last year, the NIH has put in place policies to help new investigators succeed in competing for their first major research awards. However, efforts will be successful only if funds are available to continue to support the careers of new and young investigators beyond the period of their first grant.

**The APS joins the Federation of American Societies for Experimental Biology (FASEB) and the Ad Hoc Group for Medical Research Funding in urging that NIH be provided with a 7% increase in FY 2010 to permit the agency to maintain its current wide-ranging and important research efforts.**

<sup>1</sup> M. A. Ikram *et al*, *New England Journal of Medicine* **360**, 1718-28. (April 23, 2009)

<sup>2</sup> A. M. Cypress *et al*, *New England Journal of Medicine* **360**, 1509-17. (April 9, 2009)

<sup>3</sup> A. Shapiro *et al*, *American Journal of Physiology – Regulatory, Integrative and Comparative Physiology* **295**, R1370-75. (November, 2008)

<sup>4</sup> [http://grants.nih.gov/grants/new\\_investigators/resources.htm#data](http://grants.nih.gov/grants/new_investigators/resources.htm#data) (accessed April 29, 2009)



**Testimony of the American Psychological Association**

House Appropriations Subcommittee on Labor, HHS, and Education, Fiscal Year 2010

Contact Patricia Kobor, (202) 336-5933, [pkobor@apa.org](mailto:pkobor@apa.org)

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the United States and is the world's largest association of psychologists. APA's membership includes more than 150,000 researchers, educators, clinicians, consultants and students. Through its divisions in 54 subfields of psychology and affiliations with 60 state, territorial and Canadian provincial associations, APA works to advance psychology as a science, as a profession and as a means of promoting human welfare. APA is grateful for the opportunity to submit written testimony on goals for the Fiscal Year 2010 appropriations bill for the Departments of Labor, Health and Human Services and Education. Below we enumerate recommendations for specific programs.

**Bureau of Health Professions, *Graduate Psychology Education Program*.** The APA requests that the Subcommittee include \$7 million for the Graduate Psychology Education Program (GPE) within the Health Resources & Services Administration. This nationally competitive grant program provides integrated health care services to underserved communities-- those individuals most in need of mental and behavioral health support with the least access to these services, including children, older adults, chronically ill persons and victims of abuse or trauma.

Since 2002, GPE grants have provided interdisciplinary training for approximately 2,500 graduate students of psychology and other health professions to provide integrated health care services to underserved populations. There have been 70 grants in 30 states. Students benefiting from GPE grants have worked with over 30 different types of health professionals, including physicians (e.g., pediatricians, neurologists, oncologists, endocrinologists, surgeons and psychiatrists), nurses, dentists, pharmacists, occupational therapists, and social workers. GPE funding has allowed programs to double the number of students they are able to train: and more students trained means more impact on underserved populations. The GPE Program currently supports training grants at 18 academic institutions and training sites (e.g., children's and VA hospitals) throughout the nation. All of the approximately 900 psychology graduate students who benefited from GPE funds are expected to work with underserved populations and 34-100% will be working in underserved areas immediately after completing the training.

Currently authorized under the Public Health Service Act [P.L. 105-392 Section 755 (b)(1)(J)] and funded under the "Allied Health and Other Disciplines" account in the Labor-HHS Appropriations Bill, this program has proven effective for meeting the growing health needs of our nation's least served communities. This year, specific authorizing legislation has been introduced in the U.S. Senate (S 811) as well as in the U.S. House of Representatives (HR 2066).

Without GPE, the nation would lose its critical mechanism to ensure the interdisciplinary training and placement of psychologists who specialize in underserved populations in communities with shortages of mental & behavioral health providers. This program is a critical component in the national discussion over health care reform and improvement. All leading health indicators have a behavioral component. The GPE program specifically seeks to support our nation's aging and veteran populations. Twenty percent of people over 55 suffer from a mental disorder (2005); mental disorders affect physical health and the ability to function (2008); and approximately 70% of all primary care

visits by older adults are driven by psychological factors. In addition, older adults with chronic illnesses such as heart disease have higher rates of depression than those medically well, and depression lowers immunity and may compromise a person's ability to fight infection (2008). One in five military personnel returning from Iraq and Afghanistan report symptoms consistent with major depression, generalized anxiety or post-traumatic stress disorder (PTSD) (2008). According to the Pentagon the number of U.S. troops diagnosed by the military with PTSD jumped nearly 50 percent from 2006 to 2007 as more troops served lengthy and repeated tours in Iraq and Afghanistan (2008). Furthermore, the US Army reported in May (2008) that more U.S. soldiers committed suicide in 2007 than at any time since the first Gulf War.

Providing \$7 million in FY 2010 would allow for 30 additional GPE grants including those that focus solely on the needs of older adults and returning military personnel and their families. There are approximately 900 eligible universities, professional schools and hospitals in every state nationwide.

#### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

##### ***Garrett Lee Smith Memorial Act Programs – Campus Suicide Prevention Program.***

APA encourages the Subcommittee to increase funding for the programs at SAMHSA authorized by the Garrett Lee Smith Memorial Act, especially the Campus Suicide Prevention program.

The Campus Suicide Prevention program is a small but important program that seeks to assist college and universities raise awareness about mental and behavioral health to prevent suicides. By providing educational materials and outreach, the Campus Suicide Prevention program, working in centers on campus that provide mental and behavioral health services to students, increases awareness about the signs of and risks of mental health problems and ensures greater success in college completion for those at risk of school failure because of concerns like stress, depression, eating disorders, risk behaviors and suicidal thoughts.

There is a special need to increase funds for this program during the difficult economic times facing our nation. A recent APA survey found that 18-29 year olds felt the economy added to their stress more than other concerns, like relationships or housing, a change from past years. The American College Counseling Association's 2008 Survey of College Counseling Center Directors found that "95% of directors report that the recent trend toward greater number of students with severe psychological problems continues to be true on their campuses." Further, the Survey findings note that "58% of counseling center clients report that counseling has helped them remain enrolled in their institutions, and 61% indicate, on evaluation forms, that counseling has helped with their academic performance." College counseling centers across the nation are overwhelmed. Addressing the mental and behavioral health needs of students in college and university settings can mean the difference between school failure or graduation on one hand, and life and death on the other.

**Center for Mental Health Services, *Minority Fellowship Program (MFP).*** While minorities are projected to comprise 40 percent of the U.S. population by 2025, only 23 percent of recent doctorates in psychology, social work and nursing were awarded to minorities. The MFP's mission is to address this need by increasing the number of minority mental health professionals and by training mental health professionals to become culturally competent. APA urges Congress to fund the Minority Fellowship

Program at \$7.5 million for FY 2010. Increased funding is urgently needed given the recent expansion of the program by granting eligibility to additional professions.

***Emergency Mental Health and Traumatic Stress Services Branch: Child Trauma.***

Traumatic events can have a significant impact on the physical, mental, emotional, and behavioral health of children and families. SAMHSA has made tremendous efforts in this area through the outstanding National Child Traumatic Stress Network program and its coordinating center, the UCLA-Duke University National Center for Child Traumatic Stress. APA urges Congress to appropriate full funding for the National Child Traumatic Stress Initiative at the originally authorized level of \$50 million for FY 2010. To ensure continuity of leadership in this program, APA recommends the Committee encourage SAMHSA to expand the duration of NCTSI grant awards from 3 years to 6 years.

***Center for Substance Abuse Prevention (CSAP): Substance Use and Mental***

***Disorders of Persons with HIV.*** According to recent reports, almost half of those with HIV/AIDS screened positive for illicit drug use or mental disorders, including depression and anxiety. Unfortunately, health care providers fail to detect mental disorders and substance use problems in almost half of patients with HIV/AIDS. Mental health and substance use screening is not always practiced in primary care. Several diagnostic screening tools are available for use by non-mental health staff. APA encourages SAMHSA and CDC to collaborate with HRSA to train health care providers to screen HIV/AIDS patients for mental health and substance use problems.

***Department of Health and Human Services***

***Lifespan Respite Program: Family Caregivers.*** Family caregivers play an essential role in providing a significant proportion of our nation's health and long-term care for those who are chronically ill and aging. Respite can provide family caregivers with relief necessary to maintain their own health, bolster family stability and well-being, and avoid or delay more costly nursing home or foster care placements. Under the Lifespan Respite Care Program, funds are available to improve access to respite for family caregivers. APA urges Congress to fund the Lifespan Respite Care Program at its authorized level of \$71.1 million for FY 2010.

***Centers for Disease Control and Prevention (CDC)***

***National Center for Injury Prevention and Control: Child Maltreatment Prevention at Community Health Centers (CHCs).*** APA recommends the implementation of at least ten demonstration projects of evidence-based preventative parenting programs through CHCs. Technical assistance to demonstration sites should be provided by organizations with expertise in parent-child relationships, parenting programs, prevention of child maltreatment, and the integration of behavioral health in primary and community health center settings. APA recommends evaluating the demonstration projects' implementation and outcomes, including health and mental health outcomes, cost effectiveness, patient satisfaction, program local adaptation, improvement of parent-child relationship, child and family functioning, and reduction of child maltreatment and injuries. APA also supports education, recruitment, and training of mental health and primary care providers to implement such programs and screenings at the Centers.

***National Center for Health Statistics (NCHS): Eating Disorders.*** Eating disorders are a significant public health problem for individuals across the lifespan. They may have serious, chronic effects on one's quality of life and often co-occur with significant physical and mental health problems. However, the impact of these disorders has not yet been appropriately investigated. APA urges the Committee to encourage CDC to

increase support for surveillance and research efforts regarding the incidence, morbidity, and mortality rates of eating disorders, including anorexia nervosa, bulimia nervosa, binge eating disorder, and eating disorders not otherwise specified across age, ethnicity and gender subgroups.

***Sexual and Gender Identity Inclusion in Health Data Collection.*** Health benchmark surveys commissioned by the federal government are instrumental in assessing and addressing health disparities in subpopulations. The National Health Interview Survey (NHIS) is the most comprehensive and widely referenced federal health statistics survey, yet currently does not include any question concerning sexual orientation and gender identity. APA recommends the allocation of an additional \$2 million in funding for NHIS in the NCHS budget, to enable government agencies to better understand and plan for the unique health needs of lesbian, gay, bisexual, and transgender individuals.

***Administration for Children and Families: Sexualization of Girls.*** Throughout U.S. culture, female children, adolescents, and adults are frequently depicted and treated in a sexualized manner that objectifies them. Research links sexualization with three of the most common mental health problems of female children, adolescents, and adults: eating disorders, depression or depressed mood, and low self-esteem. APA encourages HHS to fund media literacy and youth empowerment programs to prevent and counter the effects of the sexualization of female children, adolescents, and adults.

***National Institutes of Health (NIH).*** APA supports the request of the Ad Hoc Group and Coalition for Health Funding, urging an increase of at least 7% for the NIH. Years of sub-inflation budgets have stressed the NIH research enterprise, and made sharing of resources among programs more difficult. The FY 09 increase provided by Congress begins to ameliorate the budget difficulties, but scientific research will benefit from a smooth, steady and predictable rise in spending.

APA likewise supports an increase of 7 percent (to \$28.61 million) for the NIH Office of Behavioral and Social Sciences Research in the Office of the Director. This small but important office coordinates behavioral and social science research initiatives across institutes and centers, and helps form partnerships to leverage the intellectual and monetary resources that make good science possible.

The behavioral and social sciences are leading proponents of cooperation and cost-sharing in cross-cutting NIH initiatives. APA supports NIH's decision to authorize a Basic Behavioral and Social Sciences Research "Blueprint," to which several institutes would contribute, to strengthen NIH funding of basic research in the behavioral and social sciences. This innovation will build creative cooperation and cost-sharing, and help plug gaps in NIH-supported basic research.

A key area of cooperation is in research on obesity. Given the role of obesity as a risk factor for the development of cardiovascular disease, diabetes, cancer, and arthritis, many of NIH's institutes are collaborating with investigators and other institutes to develop new ways to prevent and treat obesity and overweight as well as fostering the adoption of positive health behaviors. Clearly, cultural, societal and environmental factors play a large role in the development of unhealthy behaviors that lead to obesity. While looking at the interaction between genetics and environmental factors, there is a significant impact of the social context—e.g. schools, neighborhoods, and the larger built environment-- that influences health behaviors and nutritional choices.

The Eunice Kennedy Shriver National Institute of Child Health and Human Development supports research into physical activity and eating behaviors and that examines the impact of family and peer support, developmental and social context, school-based interventions, which include the use of media and literacy, motivation, and use of various behavioral approaches to influence motivation in physical activity, food choices, and media use. The National Institute of Diabetes, Digestive and Kidney Diseases is also looking at the broader environmental factors, including land use, building design, transportation systems, access to public resources like parks that influence health behaviors. Each of these institutes is also represented on the NIH Obesity Research Taskforce to assist in the coordination of these efforts. In addition, NIAAA has led an initiative on adoption of healthy behaviors that may aid and influence research on multiple conditions.

Alcohol and tobacco use are among the leading causes of death and disability in the United States, but NIH research funding to prevent, understand the etiology of, and treat tobacco and alcohol addiction is not commensurate with the public health burden of those diseases. APA suggests that as the NIH Scientific Management Review Board (SMRB) undertakes its review of the NIH organizational structure to optimize the research of substance use, abuse and addiction, that it also quantify the amount of NIH research funding dedicated to studies of alcohol, tobacco use and illicit substance use. Further, APA recommends that the SMRB evaluate the proportion of all substance use research funding at NIH compared to CDC estimates of the public health burden of disease (and costs to the criminal justice system) and consider a reapportionment of NIH funding to Institutes based on those findings.

#### **Department of Education**

##### **Office of the Director (OD): *Culturally and Linguistically Appropriate Education.***

Ethnically diverse children and American Indian/Alaska Native children are performing at far lower levels than other students. APA urges the Committee to increase support for educational systems and the strengthening of programs that meet the unique cultural, linguistic and educational needs of ethnic minority and AI/AN students from pre-school to graduate-level education.

**Office of Safe and Drug-Free Schools: *Bullying Prevention.*** Bullying directly affects about one-third of American school children in a given semester. Research demonstrates that bullying poses serious risks for victims and bullies and may seriously affect the climate of schools. APA urges appropriate federal funding to support the implementation of effective, research-based, and comprehensive bullying prevention programs.

##### **National Institute on Disability and Rehabilitation Research: *Disability Research.***

APA recommends that NIDRR pursue mental health-related research proposals through its investigator-initiated and other grants programs, and sponsor studies on the impacts of socio-emotional, behavioral and attitudinal aspects of disability. APA encourages broad initiatives including Health and Functioning, Community Integration and Employment to address societal barriers, such as stigmatization and discrimination.

##### ***Elementary and Secondary School Counseling Program.***

APA requests that the Subcommittee increase funds for the Elementary and Secondary School Counseling program. Authorized by the Elementary and Secondary Education Act's Fund for the Improvement of Education, this program increases the range, availability, quantity, and quality of counseling services in the elementary and secondary schools across the country. Providing counseling and psychological services to students at the elementary and secondary level lay the foundation for building this future success.



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*Protect. Prevent. Live Well*

Testimony of the American Public Health Association (APHA)  
Concerning the Public Health Service Budget for Fiscal Year 2010  
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and  
Human Services and Education  
May 1, 2009

The American Public Health Association (APHA) is the oldest and most diverse organization of public health professionals and advocates in the world dedicated to promoting and protecting the health of the public and our communities. We are pleased to submit our views on federal funding for public health activities in fiscal year 2010.

**Recommendations for Funding the Public Health Service**

APHA's budget recommendations for the Public Health Service includes funding for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH), as well as agencies outside the Subcommittee's jurisdiction—the Food and Drug Administration (FDA) and the Indian Health Service (IHS).

**CDC**

APHA believes that Congress should support CDC as an agency—not just the individual programs that it funds. We support a funding level for CDC that enables it to carry out its mission to protect and promote good health and to assure that research findings are translated into effective state and local programs.

In the best judgment of APHA—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs, and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least \$8.6 billion for CDC's "core programs" in FY 2010. This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).

APHA appreciates the Subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, and environmental health programs at CDC. We also appreciate the support you provided in the economic recovery legislation for public health and prevention and wellness funding. By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments,

supporting a trained workforce, laboratory capacity and public health education communications systems. In addition, CDC is certain to play an important role as Congress considers legislation to reform the nation's health system.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak. This has been demonstrated most recently by CDC's quick response and ongoing investigation into human infections with H1N1 flu (swine flu) in the United States and internationally.

CDC's budget has actually shrunk since 2005 in terms of real dollars. According to an analysis by the Campaign for Public Health, had CDC's budget for its core programs kept up with inflation, it would be more than \$6.8 billion – about \$220 million more than the amount appropriated for CDC in the FY 2009 Omnibus bill. We are grateful for the \$239 million increase in FY 09, but we have a long way to go especially in these challenging times when public health is being asked to do more, not less. We must make up the lost ground and fully fund CDC's core public health programs at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. We strongly encourage the Subcommittee to fully fund the state and local capacity grants through the Public Health Emergency Preparedness (PHEP) cooperative agreement. This funding is down from \$919 million in FY 05 to \$746 in the FY09 Omnibus. We ask the Subcommittee to restore this program to at least \$919 million to ensure that our states and local communities can be prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Public health programs delivered at the state and local level should be flexible to respond to state and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. We greatly appreciate the work of the Subcommittee to begin restoring the Block Grant and urge that the funding be restored further to at least the FY05 level of \$131 million.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. APHA members are committed to ending the disparities. We encourage the Subcommittee to provide \$60 million for CDC's REACH program.

We also encourage the Subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. The agencies that carry out these services are fragmented and their resources are

stretched. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, E. coli and lead in drinking water. We encourage the Committee to provide \$62.3 million for CDC's Environmental Health Laboratory and \$50 million for the National Environmental Health Outcome Tracking Network. We ask that the Subcommittee continue its recent efforts to expand and enhance CDC's capacity to help the nation prepare for and adapt to the potential health effects of climate change by providing CDC with \$50 million for climate change and health activities. Expanded funding would allow CDC to: establish a research coordinating center and act as the lead agency to pull together a coordinating work group on climate change and health research; create a federal Interagency Task Force on Climate Change and Health to assess the public health implications of major climate, energy, transportation, agricultural, and other sectoral policies; develop preparedness strategies for climate change tailored to local hazards and local needs; and fund academic "Centers of Excellence" at universities to conduct climate change and health research.

#### **HRSA**

Through its programs in every state and thousands of communities across the country, HRSA is a national leader in providing a health safety net for medically underserved individuals and families, including 86.7 million Americans who were uninsured for some or all of 2007-2008; 50 million Americans who live in neighborhoods where primary health services are scarce; more than one million people living with HIV/AIDS, and 34 million vulnerable mothers and children, including children with special health needs. **To respond to this challenge, the agency will require an overall funding level of at least \$8.5 billion in FY 2010.**

For several years, HRSA has suffered from relatively level funding, undermining the ability of its successful programs to grow. Our request reflects the minimum amount necessary for HRSA to adequately meet the needs of the populations they serve in FY 2010, especially during these difficult economic times that are causing an increase in demand for HRSA programs and funding. Much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services for all; eliminating health disparities; and rebuilding the public health and health care infrastructure.

APHA appreciates the \$2.5 billion HRSA received in the American Recovery and Reinvestment Act of 2009 for community health centers and health professions workforce development to prepare our health infrastructure for health system reform. This investment recognizes the critical role HRSA plays in building the foundation for health service delivery. However, we urge the Subcommittee to support adequately funding all of HRSA's broad health programs and ensure that vulnerable populations transition smoothly into a new health system and receive continued, quality health services. By supporting, planning for and adapting to change, we can build on the successes of the past and address the new gaps that emerge as a result of health system reform.

Our \$8.5 billion funding request is based on the authorized amounts and estimated needs of HRSA's various programs. It includes \$2.602 billion for the Health Centers program, the fully authorized level under the Health Care Safety Net Act of 2008, as part of a long-term plan to provide care to 30 million Americans by 2015. Thanks to the leadership of the Subcommittee, more than 7,000 health centers in every state and territory provide a health care home for more than 18 million medically underserved and low-income patients, and demand for their services continues to grow. The Health Centers program targets populations with special needs, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing. Health centers provide access to high-quality, family-oriented, culturally and linguistically competent primary care and preventive services, including mental and



behavioral health, vision, and dental services. While recent growth in the health centers program has been substantial, a significant need remains in underserved communities across the country. APHA strongly encourages the Subcommittee to continue its support of existing health centers and efforts to expand the reach and scope of the Health Centers program into new communities.

APHA recommends \$550 million for health professions programs under Title VII and VIII of the Public Health Service Act. These programs are an essential component of America's health safety net and work in concert with the Health Centers Program and National Health Service Corps to enhance the supply, distribution and diversity of the health professions workforce. They are the only federal programs that support the education and training of primary care providers in interdisciplinary settings to work in underserved communities and increase minority representation in the health professions workforce. Through loans, scholarships and grants to academic institutions and non-profit organizations, these programs provide support for the training of primary care physicians, nurses, dentists, physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, pharmacists, health educators, and other allied health providers. Adequate funding will reduce provider shortages in rural, medically underserved and federally designated health professions shortage areas and strengthen the pipeline of new providers that Health Centers and other safety-net health facilities need to meet the long-term needs of underserved communities. In addition, APHA recommends funds be appropriated to re-establish the National Center for Health Workforce Analysis to conduct and support statistical and epidemiological activities for assessing and improving decision-making to enhance the supply, distribution, diversity, and development of the current and future public health workforce. We also recommend that support be included for optometrists who are eligible for Title VII programs but have never received funding.

The Office of Rural Health Policy promotes better health services for the 60 million Americans who live in rural communities. These communities suffer from inadequate access to quality health services and experience the higher rates of illness associated with lower socioeconomic status. Rural Health Outreach and Network Development Grants, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas. In addition, Rural Health Research Centers help policymakers better understand the challenges that rural communities face in assuring access to health services and improving the health of their residents. APHA encourages the Subcommittee to adequately fund these important programs that address the many unique health service needs of rural communities.

Poison Control Centers, also administered by the Healthcare Systems Bureau, are a critical resource for people, health professionals and organizations. Poisoning can happen to anyone, at anytime in any place and can lead to serious illness or even death. Each year, more than two million possible poisonings are reported to the nation's poison centers. On average, poison centers handle one possible poisoning every 13 seconds. These critical centers cannot afford to lose any resources and we encourage the subcommittee to fully fund this program.

Finally, APHA recommends a significant funding increase for HRSA's program management and staffing needs. Since 2001, HRSA has experienced a decline of almost 600 full-time equivalent employees. While HRSA has continued to administer its many programs effectively, the agency is facing ever growing demands as a result of the economic crisis and a changing health system. We strongly urge the Subcommittee to increase program management funds to provide the agency with the necessary human and other resources to ensure the programs it administers are effective and improve the health of the American public.

**AHRQ**

We request a funding level of at least **\$405 million for AHRQ for FY 2010**. This level of funding is needed for the agency to fully carry out its Congressional mandate to conduct, support, and disseminate research and translate research into knowledge and information that can be used to improve the health of all Americans. AHRQ focuses on improving health care quality, eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities.

**SAMHSA**

APHA supports a funding level of **\$3.92 billion for SAMHSA for FY 2010**. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

**NIH**

APHA supports a funding level of **\$32.4 billion for the NIH for FY 2010**. The translation of fundamental research conducted at NIH provides some of the basis for community based public health programs that help to prevent and treat disease.

**FDA**

While understand the FDA is funded through the Agriculture Subcommittee, given the agency's public health mission, we want you to be aware of our support for a funding level of **\$2.425 billion for FY 2010**. It is essential that we provide FDA with the resources it needs to assure the safety of our food and the safety and efficacy of drugs and medical devices.

**IHS**

APHA supports adequately funding IHS so that health care programs accessed by American Indian/Alaska Native are funded at levels equal to the rest of the nation's citizens. APHA urges the Subcommittee to provide an **additional \$18.5 million in FY 2010 for the loan repayment account** to allow the IHS to hire and keep needed health care providers.

**Conclusion**

In closing, we emphasize that the public health system requires stronger financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. This is especially critical given the important role that CDC, HRSA and other public health agencies and programs will likely play as Congress works to reform the nation's health system.

We thank the subcommittee for the opportunity to present our views on the FY 2010 appropriations for public health service programs.



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**Statement  
Of the  
AMERICAN PUBLIC POWER ASSOCIATION  
Submitted to the  
HOUSE APPROPRIATIONS COMMITTEE'S  
SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES  
April 17, 2009**

The American Public Power Association (APPA) is the national service organization representing the interests of over 2,000 municipal and other state and locally owned utilities throughout the United States (all but Hawaii). Collectively, public power utilities deliver electricity to one of every seven electricity consumers (approximately 45 million people), serving some of the nation's largest cities. However, the vast majority of APPA's members serve communities with populations of 10,000 people or less.

We appreciate the opportunity to submit this statement supporting funding for the Low-Income Home Energy Production Assistance Program (LIHEAP) for Fiscal Year (FY) 2010.

APPA has consistently supported an increase in the authorization level for LIHEAP. The Administration's FY 2010 budget requests \$3.2 billion for LIHEAP. APPA supports a level of \$5.1 billion for the program.

APPA is proud of the commitment that its members have made to their low-income customers. Many public power systems have low-income energy assistance programs based on community resources and needs. Our members realize the importance of having in place a well-designed low-income customer assistance program combined with energy efficiency and weatherization programs in order to help consumers minimize their energy bills and lower their requirements for assistance. While highly successful, these local initiatives must be coupled with a strong LIHEAP program to meet the growing needs of low-income customers. In the last several years, volatile home-heating oil and natural gas prices, severe winters, high utility bills as a result of dysfunctional wholesale electricity markets and the effects of the economic downturn have all contributed to an increased reliance on LIHEAP funds.

Also when considering LIHEAP appropriations this year, we encourage the Subcommittee to provide advanced funding for the program so that shortfalls do not occur in the winter months during the transition from one fiscal year to another. LIHEAP is one of the outstanding examples

of a state-operated program with minimal requirements imposed by the federal government. Advanced funding for LIHEAP is critical to enabling states to optimally administer the program.

Thank you again for this opportunity to relay our support for increased LIHEAP funding for FY 2010.

**Statement of the American Society for Microbiology submitted to  
the House Committee on Appropriations Subcommittee on Labor, Health &  
Human Services, Education, and Related Agencies  
on FY 2010 Funding for the  
National Institutes of Health**

The American Society for Microbiology (ASM) appreciates the opportunity to submit a written statement on the FY 2010 budget for the National Institutes of Health (NIH). The ASM is the largest single life science society with over 42,000 members, many of whom receive funding from the NIH. We are grateful for the \$10.4 billion increase in funding for the NIH in the American Recovery and Reinvestment Act (ARRA) and the 3.2 percent increase in funding for NIH in the FY 2009 Appropriations Act. The additional ARRA funding enables NIH to support the ARRA goals to create and save jobs and increase purchasing power, as well as advance scientific research. The nation's biomedical research enterprise will be kept more robust at a time when it is experiencing the adverse effects of the economic downturn and years of flat funding.

As Congress considers the FY 2010 appropriation for NIH, the ASM recommends a budget of \$32.4 billion, a 7 percent increase. The recommended funding increase will help NIH keep pace with expanded research opportunities and higher costs. It is important for NIH to prepare for the post-stimulus years, in 2011 and beyond. It is also important to resume sustainable NIH funding, avoiding fluctuations for research and training programs that can disrupt projects, training, careers and research progress. To perpetuate the benefits of ARRA funding, it is vitally important to provide sustained growth for the NIH in FY 2010 and beyond.

Over 83 percent of the NIH budget is awarded through 50,000 competitive grants awarded to more than 325,000 researchers at over 3,000 universities, medical schools, and other institutions in all 50 states. About 10 percent of the NIH budget supports research in NIH laboratories conducted by nearly 6,000 scientists. Research project grants are highly productive in terms of medical advances to benefit public health. NIH funding contributes to the nation's economic recovery by stimulating new opportunities and investments in biotechnology and related industries, as well as expanding the skilled workforce critical to US competitiveness in science and technology. NIH funding also impacts allied health workers, technicians, students, trade workers and others who receive the leveraged benefits from NIH funding.

The following describes some of the compelling reasons for increased and sustained support for the NIH research mission and its proven benefit to technological innovation and public health.

**NIH Research is Critical to Scientific Progress**

NIH institutes and centers fund research programs that address the nation's challenges of safeguarding public health, security, and the economy. The National Institute of Allergy and Infectious Diseases (NIAID), for example, focuses on research to understand, treat, and prevent infectious, immunologic, and allergic diseases, leading to the development of vaccines, therapies and diagnostic tools. The NIAID also funds research on medical countermeasures against potential bioterror agents. The National Institute of General Medical Sciences (NIGMS) supports

basic research on life processes in fields such as computational biology, genetics, and bioinformatics. NIH resources invested in the agency-wide Roadmap initiatives make possible projects that hold great potential but might otherwise not be funded due to difficulty and scope. Recently funded Roadmap projects include a network of nine centers using high-tech screening methods for drug discovery.

The NIH funding to individual researchers and research groups, through competitive peer-reviewed grants, is of particular consequence to the US research enterprise. More than 120 discoveries made by NIH and NIH-supported researchers have garnered Nobel Prizes, and NIGMS has funded the Nobel Prize-winning work of 64 scientists. More than three-fourths of the US recipients of the Nobel Prize in Physiology or Medicine received NIH support prior to their award. In FY 2009 NIH is striving to lower the average age of first-time grant recipients to refresh the nation's scientific investigator pool and help revitalize research in the United States. Our national anxiety over waning global competitiveness and a shrinking technical workforce argues for sustained NIH funding for both new and established investigators.

NIH investigator initiated grants create new opportunities for original biomedical inquiry and expand training environments for students in technical fields. Investigator-initiated research projects lead to inventive solutions for medical problems. Each year, NIH also identifies, in consultation with the extramural research community, targeted areas within an emerging need or opportunity, and then requests grant applications from US researchers. Focused opportunities announced last year by NIAID include studies to advance vaccine safety and development of assays for high-throughput drug screening. NIGMS-featured areas currently include computational models to detect, control and prevent emerging infectious diseases. NIGMS also awards grants for nontraditional research through its Exceptional, Unconventional Research Enabling Knowledge Acceleration (EUREKA) program. NIH has placed new emphasis on supporting high-impact transformative research that might create new disciplines, revolutionary technologies, or otherwise radically change biomedical research. In 2008, it initiated transformative grant funding to foster investigator-initiated work considered high-risk but exceptionally promising.

#### **NIH Research Yields Medical Advances**

NIH supported research consistently produces significant discoveries with both real-world relevance and potential future use against emerging health threats. The following are selected examples of recently reported research that illustrate the vitality and creativity supported by NIH funding.

**Antimicrobial Resistance and Drug Discovery.** Drug resistance spreading among microbial pathogens is complicating control of infectious diseases and adding to rising health care costs. Response by US research institutions has been aggressive, including creation of a Federal Interagency Task Force co-chaired by NIAID, the Centers for Disease Control and Prevention, and the Food and Drug Administration. Causes of drug resistance are many, from overuse of prescription drugs to natural microbial mutations, and NIAID's research portfolio is equally diverse. In FY 2007, the Institute invested more than \$800 million to support basic and translational research on antimicrobials and on drug resistance. Recent results include:

- Scientists from NIAID, California, and China studied the genetics of the major strain of methicillin-resistant *Staphylococcus aureus* (MRSA), concluding that a radical shift may be needed in how scientists design MRSA therapeutics. MRSA causes an estimated 94,000 cases of infection annually in the United States, with over 19,000 deaths.
- NIGMS-funded researchers are developing a new generation of antibiotic compounds that do not elicit drug resistance. The enzyme-inhibitor compounds interfere with "quorum sensing"—a process by which bacteria communicate with each other. Those in the current study work against *Vibrio cholerae*, which causes cholera, and *E. coli* 0157:H7, the food contaminant that annually causes about 110,000 illnesses in the United States.

To circumvent antimicrobial resistance, NIH researchers and their extramural collaborators are intensifying research strategies better suited to rapidly changing pathogens and disease demographics. These include state-of-the-art technologies that fuel 21<sup>st</sup> century drug discovery. A recent example is NIGMS-funded research using mass spectrometry technology to determine the molecular structure of a class of natural compounds called nonribosomal peptides (NRPs), intensely studied for their drug potential (penicillin is an NRP). A significant advance over previous approaches, it may help reprogram nonpathogenic *E. coli* into NRP minifactories.

**Infectious Diseases.** Infectious diseases remain among the most difficult global health challenges, accounting for about one-quarter of all deaths and nearly two-thirds in sub-Saharan Africa. At NIAID and NIGMS, multiple programs and interdisciplinary strategies target the major causes of global death and disability, with cutting-edge tools like genomics and nanotechnology.

**Influenza** Despite the availability of influenza drugs and vaccines, seasonal influenza still kills more than 250,000 people worldwide each year. Public health officials are now concerned about reports that 98 percent of a H1N1 influenza virus strain (one of three circulating in the 2008-2009 season) are resistant to oseltamivir (Tamiflu), the leading influenza drug, compared to 11 percent resistance among all viral strains during the 2007-2008 season. The possibility of an influenza pandemic caused by the more lethal H5N1 avian flu virus has mobilized an international response from health agencies and medical researchers. In January, the Department of Health and Human Services awarded a contract to build the first US manufacturing facility for cell-based influenza vaccines, expected to increase the nation's current capacity to make vaccine by at least 25 percent and much less time. NIH funding contributed to this major advance in vaccine production and to other recent advances, such as:

- NIAID-supported scientists used new monoclonal techniques to create human influenza-fighting antibodies in the laboratory in a matter of weeks, rather than the months previously required. The antibodies have potential for diagnosis and treatment regimens that can respond more quickly to newly emerging strains of influenza.
- NIGMS-funded researchers used super-computer capabilities to identify more than two dozen new candidate drugs to treat avian influenza ("bird flu"), in preparation for a possible pandemic of drug-resistant H5N1 virus strains.
- Three research teams and a computer informatics group—part of the NIGMS-funded Models of Infectious Disease Agent Study (MIDAS) Network—modeled pandemic

influenza in the United States, concluding mitigation is possible with prompt, coordinated use of social-distancing measures and antiviral treatment until vaccine is available.

**HIV/AIDS** An estimated 33 million adults and children are living with HIV infection worldwide, and about 2 million die each year from related causes. In the United States, where nearly 546,000 people have died thus far from HIV/AIDS-related illnesses, there currently are an estimated 1.1 million infected, with 21 percent unaware of their infection. HIV/AIDS as both a domestic and global threat is a high priority at NIH. Difficulties in developing preventative vaccines prompted a 2008 NIH vaccine summit and subsequent reexamination of NIH's research agenda. NIH-supported basic research is steadily adding to our understanding of HIV/AIDS, evidenced by recent discoveries in mechanisms of HIV protease inhibition and the NIGMS-funded success in seeing microscopically for the first time molecules grouping in living cells to form single HIV particles. Other recent advances include:

- A vaginal gel to prevent HIV infection in women has shown encouraging signs of success in a clinical trial in Africa and the United States. This is the first human clinical study to suggest that a microbicide may prevent male-to-female sexual HIV transmission.
- An extended course of the antiretroviral drug nevirapine helps the breastfeeding babies of HIV-infected mothers remain HIV-negative and live longer, according to several new studies. About 150,000 infants worldwide acquire HIV annually through breastfeeding.
- The incidence of childhood illness and death due to HIV infection can be dramatically decreased by testing very young babies for HIV and giving antiretroviral therapy (ART) immediately to those found infected—giving ART to HIV-infected infants beginning at an average age of 7 weeks made them four times less likely to die in the next 48 weeks.

**Tuberculosis** One-third of the world's 6.7 billion people are thought to be infected by *Mycobacterium tuberculosis* (*Mtb*), the microbe that causes tuberculosis. An estimated 13.7 million have the active form. Each year, about 1.7 million die from this age-old disease that has adopted some disturbing modern-day features, striking as co-infections with the HIV virus and becoming resistant to drug therapies used to treat tuberculosis. In 2007, about 9.3 million people developed new cases of TB; 1.37 million were also HIV positive. The rapid spread of multidrug- and extensively drug-resistant forms (MDR TB/XDR TB) is alarming—MDR TB currently accounts for an estimated 5 percent of all TB cases and the frequently fatal XDR TB has been detected in 46 countries thus far. In April 2008, NIAID launched an aggressive research agenda against drug-resistant tuberculosis. NIH-supported research from the past year includes:

- NIAID scientists and industry collaborators found that, when the candidate TB drug PA-854 is metabolized inside *Mtb* bacteria, a lethal dose of nitric oxide gas is produced, killing the pathogen and suggesting new ways to develop drugs capable of killing latent TB bacteria. Currently there are no drugs available to target latent tuberculosis infections.
- Scientists reported that two FDA-approved drugs work in tandem to kill the tuberculosis pathogen and could help counter drug-resistant forms. The drugs are already used to treat other bacterial diseases, but their effectiveness against TB bacteria had not been studied. NIAID is planning a clinical trial this year in patients with MDR TB and XDR TB.



**Malaria** Nearly half of the world's population is at risk of contracting malaria, a preventable and curable mosquito-borne disease in more than 100 countries. The World Health Organization (WHO) estimates that 300 to 500 million cases of clinical malaria worldwide occur each year, killing 1.3 million people. Unfortunately, its impact is intensifying with the emergence of drug-resistant parasites and insecticide-resistant mosquitoes. In April 2008, NIAID announced its new strategic plan to accelerate malaria control and eradication. NIH research often involves international partners and encompasses all aspects of malaria, including these recent examples:

- NIGMS funding supported the genetic decoding of the parasite responsible for 40 percent of infections, *Plasmodium vivax*, one of four malaria parasites that routinely affect humans. The most common species outside Africa (including the United States), *P. vivax* is increasingly resistant to some antimalarial drugs.
- The NIAID-funded Malaria Research and Training Center in Mali completed the first clinical trial of a vaccine to block the malaria parasite from entering human blood cells.
- NIGMS-supported research described how harmless *E. coli* bacteria can be harnessed to synthesize an antimalarial compound in bulk, far less expensive than the current process.

#### **Infectious Disease Research Uses Interdisciplinary Strategies and New Technologies**

NIAID and NIGMS, like other NIH institutes and centers, support productive basic research on literally hundreds of diseases, from periodic foodborne *E. coli* or *Salmonella* outbreaks to isolated cases of Ebola fever or anthrax. This enormous responsibility forces constant adaptation to new challenges, often through greater reliance on interdisciplinary strategies or novel research tools and technologies—epitomized by the large-scale genetics-based initiatives made possible with today's powerful computing capabilities. In 2008, NIH launched a multi-Institute epigenomics initiative to better understand the role of the environment in regulating mammalian genes, through genome mapping, data analysis, and technology development. NIH also agreed to share databases from its Human Microbiome Project in support of the newly formed International Human Microbiome Consortium. Characterizing the human microbiome, which is the collective DNA of all the microbes living in or on the human body, will elucidate the relationship between microbes and humans during health and disease. Shared sample repositories overseen by databases expedite information exchange among scientists. Computerized screening of pathogen genomes similarly accelerates the search for treatments, vaccines, and diagnostics.

#### **Conclusion**

The ASM is thankful that Congress recognizes both the medical benefits and economic impacts of biomedical research and has provided an infusion of funding for the NIH to uncover new knowledge that will improve public health. Investing in NIH will impact the health of people for years to come and the biomedical community is working to ensure wise investment of the new resources in FY 2009. We are confident that investments in the NIH will result in new discoveries and innovations that can address many of our health and economic challenges.

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**Statement of the American Society for Nutrition (ASN)  
Submitted to the House Appropriations Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies on Fiscal Year 2010 Funding  
for the National Institutes of Health and the National Center for Health Statistics**

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The American Society for Nutrition (ASN) appreciates this opportunity to submit testimony regarding fiscal year (FY) 2010 appropriations for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS). ASN is the professional scientific society dedicated to bringing together the world's top researchers, clinical nutritionists and industry to advance our knowledge and application of nutrition to promote human and animal health. Our focus ranges from the most critical details of research to very broad societal applications. **ASN respectfully requests \$32.4 billion for NIH, and we urge you to adopt the President's request of \$137.5 million for NCHS in fiscal year (FY) 2010.**

Basic and applied research on nutrition, nutrient composition, the relationship between nutrition and chronic disease and nutrition monitoring are critical to the health of all Americans and the U.S. economy. Awareness of the growing epidemic of obesity and the contribution of chronic illness to burgeoning health care costs has highlighted the need for improved information on dietary components, dietary intake, strategies for dietary change and nutritional therapies. Preventable chronic diseases related to diet and physical activity cost the economy over \$117 billion annually, and this cost is predicted to rise to \$1.7 trillion in the next ten years. It is for this reason that we urge you to consider these recommended funding levels for two agencies under the Department of Health and Human Services that have profound effects on nutrition research, nutrition monitoring, and the health of all Americans—the National Institutes of Health and the National Center for Health Statistics.

**National Institutes of Health**

The National Institutes of Health (NIH) is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 90 percent (nearly \$1 billion) of federally-funded basic and clinical nutrition research. Nutrition research, which makes up about four percent of the NIH budget, is truly a trans-NIH endeavor, being conducted and funded across multiple Institutes and Centers. Some of the most promising nutrition-related research discoveries have been made possible by NIH support.

In order to fulfill the extraordinary promise of biomedical research, including nutrition research, **ASN recommends an FY 2010 funding level of \$32.4 billion for the agency, which is a 7% increase (\$2.1 billion) over FY 2009.**

Over the past 50 years, NIH and its grantees have played a major role in the explosion of knowledge that has transformed our understanding of human health, and how to prevent and treat human disease. Because of the unprecedented number of breakthroughs and discoveries made

possible by NIH funding, scientists are helping Americans to live longer, healthier and more productive lives. Many of these discoveries are nutrition-related and have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and age-related macular degeneration.

During the next 25 years, the number of Americans with chronic disease is expected to reach 46 million, and the number of Americans over age 65 is expected to be the largest in our nation's history. Sustained support for basic and clinical research is required if we are to confront successfully the health care challenges associated with an older, and potentially sicker, population.

For several years in a row the NIH budget failed to keep up with inflation and subsequently, the percentage of dollars funding nutrition-focused projects declined. We applaud Congress' inclusion of funds for NIH in H.R. 1, the American Recovery and Reinvestment Act, and also the boost provided in the FY 2009 omnibus appropriations bill. It is imperative that we continue our commitment to biomedical research and to fulfill the hope of the American people by making the NIH a national priority. Otherwise, we risk losing our nation's dominance in biomedical research.

The seven percent increase we recommend is an important step toward President Obama's campaign pledge to double funding for basic research over ten years and is necessary to maintain both the existing and future scientific infrastructure. The discovery process—while it produces tremendous value—often takes a lengthy and unpredictable path. Recent experience has demonstrated how cyclical periods of rapid funding growth followed by periods of stagnation is disruptive to training, to careers, long range projects and ultimately to progress. NIH needs sustainable and predictable budget growth to achieve the full promise of medical research to improve the health and longevity of all Americans.

#### **CDC National Center for Health Statistics**

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention (CDC), is the nation's principal health statistics agency. The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the nation's health and nutrition status. Nutrition and health data, largely collected through the National Health and Nutrition Examination Survey (NHANES), is essential for tracking the health and well being of the American population, and it is especially important for observing health trends in our nation's children. Knowing both what Americans eat and how their diets directly affect their health provides valuable information to guide policies on food safety, food labeling, food assistance, military rations and dietary guidance.

Over the past few years, flat and decreased funding levels have threatened the collection of this important information, most notably vital statistics and the NHANES. ASN was pleased to see that Congress appropriated an additional \$11 million to the agency—for nearly \$125 million total—in FY 2009. This halted what would have been the beginning of drastic cuts to the agency's premier health surveys—NHANES and the National Health Information Survey—that were slated to occur should the agency not receive additional funds.

To continue support for the agency and its important mission, **ASN recommends an FY 2010 funding level of \$137.5 million for the agency, which is a \$12.5 million increase over FY 2009.**

Current funding levels for NCHS remain precarious. Before the recent increase in funds, NCHS had lost \$13 million in purchasing power since FY 2005 due to years of flat funding, coupled with inflation and the increased costs of technology and information security. These shortfalls forced the elimination of data collection and quality control efforts, threatened the collection of vital statistics, stymied the adoption of electronic systems and limited the agency's ability to modernize surveys to reflect changes in demography, geography, and health delivery.

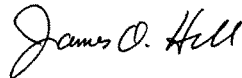
Moreover, nearly 30 percent of the funding for NHANES comes from other federal agencies such as the NIH and the Environmental Protection Agency. When these agencies face flat budgets or cuts, they withdraw much-needed support for NHANES, placing this national treasure in even greater jeopardy.

The obesity epidemic is a case in point that demonstrates the value of the work done by NCHS. It is because of NHANES that our nation became aware of this growing public health problem, and as obesity rates have increased to 31 percent of American adults (which we know because of continued monitoring), so too have rates of heart disease, diabetes and certain cancers. It is only through continued support of this program that the public health community will be able to stem the tide against obesity. Continuous collection of this data will allow us to determine not only if we have made progress against this public health threat, but also if public health dollars have been targeted appropriately. A recent report from the Institute of Medicine recognized the importance of NHANES and called for the enhancement of current surveillance systems to monitor relevant outcomes and trends with respect to childhood obesity.<sup>1</sup>

Providing an additional \$12.5 million in FY 2010 continues the progress on the path to boost funding for the NCHS to \$175 million by 2013. Reaching this level over five years, through annual increases of approximately \$11-12 million, would allow the agency to reach what its supporters call "blue sky." Such an increase would ensure uninterrupted collection of vital statistics and sustain over-sampling of vulnerable populations.

ASN thanks your Committee for its support of the NIH and NCHS in previous years. If we can provide any additional information, please contact Mary Lee Watts, ASN Director of Science and Public Affairs, at (301) 634-7112 or [mwatts@nutrition.org](mailto:mwatts@nutrition.org).

Sincerely,



James O. Hill, PhD  
President, American Society for Nutrition

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<sup>1</sup> Institute of Medicine. *Progress in Preventing Childhood Obesity* Washington, DC: National Academies Press, 2006.

Joe A. Beavo, Jr., Ph.D.  
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**Written testimony of the American Society for Pharmacology and Experimental Therapeutics to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education & Related Agencies  
 Fiscal Year 2010  
 Appropriations for the National Institutes of Health**

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health FY 2010 budget. ASPET is a 4,500 member scientific society whose members conduct basic and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases as well as increasing our knowledge regarding how therapeutics work in humans.

ASPET members recognize the trust and support that Congress displayed with the recent \$10.4 billion provided to the NIH in the American Recovery and Reinvestment Act (ARRA). This was a visionary attempt by Congress to stimulate the economy by restoring their historic support of the NIH which has lagged over the last six years as appropriations have failed to adequately fund the NIH to meet scientific opportunities and challenges to our public health. Prior to ARRA funding, the NIH research portfolio could barely keep pace with the inflation rate and the country's leadership in biomedical research was in danger. Since the completion of a bipartisan plan to double the NIH budget that ended in 2003 and prior to ARRA funding, the NIH budget had been going backwards.

For FY 2010, ASPET urges Congress to increase funding for the NIH by 7%. This would be the first step toward the President's pledge to double funding for basic research over ten years and importantly, would help to maintain existing and future scientific infrastructure. Scientific discovery takes time and a 7% increase in FY 2010 and beyond will help NIH manage its research portfolio effectively without necessitating disruptions in continuity of existing grants to researchers throughout the country. Only through sustainable and predictable funding can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country. Failing to capitalize upon the ARRA investments in FY 2010 and beyond will mean that NIH will have to dismantle newly built research capacity and terminate important research projects after the ARRA funds have been spent. This would have serious consequences for future scientific discovery. Scientific discovery takes time and is unpredictable. As recent experience has shown from the post-doubling experience, boom and bust cycles of rapid funding followed by significant periods of stagnation or retraction in the NIH budget diminish scientific process. If NIH cannot sustain its recent investments from the ARRA, a rapid diminishment of funding will further disrupt scientific careers among promising

young and early career scientists who see little hope of promising and rewarding careers in biomedical research. It is critical to avoid a boom and bust cycle for NIH funding. Thus, appropriating NIH a 7% increase beginning in FY 2010 will help achieve the full promise of biomedical research.

#### **NIH Improves Human Health and is an Economic Engine**

A 7% increase in FY 2010 will help to reverse what ASPET feels is a wrong signal that has been sent to the best and brightest of our students who will not be able to or have chosen not to pursue a career in biomedical research. Failing to address the NIH scientific and infrastructure needs post-ARRA in 2010 and beyond will mean a significant reduction in research grants, jobs lost and the resulting phasing-out of research programs. Additionally, there would be a loss of scientific opportunities to discover new therapeutic targets to develop, and fewer discoveries that produce spin-off companies that employ individuals in districts around the country. A 7% increase would provide the institutes with an opportunity to fund more high quality and innovative research, and provide the resources and incentives that will drive more young scientists to commit to careers supporting continuing improvements in public health. This investment will also go directly into supporting jobs for US citizens and residents and will continue to stimulate the economy.

Many important drugs have been developed as a direct result of the basic knowledge gained from federally funded research, such as new therapies for breast cancer, the prevention of kidney transplant rejection, improved treatments for glaucoma, new drugs for depression, and the cholesterol lowering drugs known as statins that prevent 125,000 deaths from heart attack each year. AIDS related deaths have fallen by 73% since 1995 and the five-year survival rate for childhood cancers rose to almost 80% in 2000 from under 60% in the 1970s. NIH studies have indicated that adopting intensive lifestyle changes delayed onset of type 2 diabetes by 58% and that progesterone therapy can reduce premature births by 30% in women at risk.

Historically, our past investment in basic biological research has led to innovative medicines that have virtually eliminated diphtheria, whooping cough, measles and polio in the U.S. Eight out of ten children now survive leukemia. Death rates from heart disease and stroke have been reduced by half in the past 30 years. Molecularly targeted drugs such as Gleevec<sup>TM</sup> to treat adult leukemia do not harm normal tissue and dramatically improve survival rates. NIH research has developed a class of drugs that slow the progression of symptoms of Alzheimer's disease. The robust past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenetics and a reduction in adverse drug reactions that currently represent a major worldwide health concern.

But unless NIH can maintain an adequate funding stream scientific opportunities will be delayed, lost, or forfeited to biomedical research opportunities in other countries and the human and economic cost will continue to impact all of us.

Scientific inquiry leads to better medicine and there remain many challenges and opportunities that need to be addressed. Two issues specific to ASPET highlight the need for appropriate NIH funding levels.

- The need to increase support for training and research in integrative/whole organ science. This will help to develop skilled scientists trained to understand how drugs act in whole animals, including human beings. Support for training and research in integrative whole organ sciences has been affirmed in the FY 2002 U.S. Senate Labor/Health and Human Services & Related Agencies Appropriations Report (107-84). The Senate report supports ASPET recommendation that "Increased support for research and training in whole systems pharmacology, physiology, toxicology, and other integrative biological systems that help to define the effects of therapy on disease and the overall function of the human body." These principles and recommendations are also affirmed in the FASEB Annual Consensus Conference Report on Federal Funding for Biomedical and Related Life Sciences Research for FY 2002.
- The need to meet public health concerns over growing consumer use of botanical therapies and dietary supplements. These products have unsubstantiated scientific efficacy and may adversely impact the treatment of chronic diseases, create dangerous interactions with prescription drugs, and may cause serious side effects including death among some users. Through the NIH, research into the safety and efficacy of botanical products can be conducted in a rigorous and high quality manner. Sound pharmacological studies will help determine the value of botanical preparations and the potential for their interactions with prescription drugs as well as chronic disease processes. This research will allow the FDA to review the available pharmacology and review valid evidence-based reviews to form a valid scientific foundation for regulating these products.

### **Conclusion**

NIH and the biomedical research enterprise face a critical moment. For the first time in six years, NIH has the potential to meet many of the more promising scientific opportunities that currently challenge medicine. Reversing the trends of the last half decade is only part of the solution. In order to help sustain scientific progress it is critical that NIH receive 7% to continue the progress made under the ARRA. A 7% increase for the NIH in FY 2010 will permit the NIH to make greater strides to prevent, diagnose and treat disease, improving the health of our nation and restoring the NIH to its role as a national treasure that attracts and retains the best and brightest to biomedical research.





## American Society of Plant Biologists

Official Written Testimony for Fiscal Year 2010 Budget  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Committee on Appropriations  
United States House of Representatives  
Washington, D.C.

Submitted by  
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and  
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May 1, 2009

On behalf of the American Society of Plant Biologists (ASPB) we would like to thank the Subcommittee for its extraordinary support of the National Institutes of Health (NIH) and ask that the Subcommittee Members encourage increased funding for plant biology research, which has contributed in innumerable ways to improving the lives of people throughout the world.

The American Society of Plant Biologists is an organization of more than 5,000 professional plant biologists, educators, graduate students, and postdoctoral scientists. A strong voice for the global plant science community, our mission – which is achieved through engagement in the research, education, and public policy realms – is to promote the growth and development of plant biology and plant biologists and to foster and communicate research in plant biology. The Society publishes the highly cited and respected journals *Plant Physiology* and *The Plant Cell*, and it has produced and supported a range of materials intended to demonstrate fundamental biological principles that can be easily and inexpensively taught in school and university classrooms by using plants.

### Plant Biology Research and America's Future

Plants are vital to our very existence. They harvest sunlight, converting it to chemical energy for food and feed; they take up carbon dioxide and produce oxygen; and they are almost always the primary producers in the Earth's ecosystems. Plants and plant-based products directly or indirectly provide our food, our shelter, and our clothing.

Basic plant biology research is making many fundamental contributions in vital areas including health and nutrition, energy, and climate change. For example, because plants are the ultimate source of both human nutrition and nutrition for domestic animals, plant biology has the potential to contribute greatly to reducing health care costs as well as playing an integral role in drug discovery and therapies. *Although the National Institutes of Health does offer some funding support to plant biology research, with increased funding plant biologists can offer much more to advance the missions of the National Institutes of Health.* In the next section, we highlight the particular relevance of plant biology research to human health.

### Plant Biology and the National Institutes of Health

The mission of the NIH is to pursue “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability” (<http://www.nih.gov/about/index.html#mission>). Plant biology research is highly relevant to this mission.

Plants are often the ideal model systems to advance our “fundamental knowledge about the nature and behavior of living systems,” as they provide the context of multi-cellularity, while affording ease of genetic manipulation, a lesser regulatory burden, and inexpensive maintenance requirements. Many basic biological components and mechanisms are shared by both plants and animals. For example, a molecule named cryptochrome that senses light was identified first in plants and subsequently found to also function in humans, where it plays a central role in regulating our biological clock. Jet lag provides one familiar example of what happens to us when our biological clock is disrupted, but there are also human genetic disorders that have been linked to malfunctioning of the clock. As another example, some fungal pathogens can infect both humans and plants.

#### *Health and Nutrition*

Plant biology research is also central to the application of basic knowledge to “extend healthy life and reduce the burdens of illness and disability.” This connection is most obvious in the inter-related areas of nutrition and clinical medicine. Without good nutrition, there cannot be good health. One World Health Organization study on childhood nutrition in developing countries concluded that over 50% of the deaths of children less than five years of age could be attributed to malnutrition's effects in exacerbating illnesses such as respiratory infections and diarrhea. In other words, those illnesses would not have proved fatal had the children simply

received proper nutrition. Strikingly, most of these deaths were not linked to severe malnutrition but only to mild or moderate nutritional deficiencies. Plant biology researchers are working today to improve the nutritional content of crop plants by, for example, increasing the availability of nutrients and vitamins such as iron, vitamin E and vitamin A. (Up to 500,000 children in the developing world go blind every year as a result of vitamin A deficiency).

By contrast, obesity, cardiac disease, and cancer take a striking toll in the developed world. Among many plant biology initiatives relevant to these concerns are research to improve the lipid composition of plant fats and efforts to optimize concentrations of plant compounds that are known to have anti-carcinogenic properties, such as the glucosinolates found in broccoli and cabbage.

#### *Drug Discovery*

Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, over 10% of the drugs considered by the World Health Organization to be “basic and essential” are still exclusively obtained from flowering plants. Some historical examples are quinine, which is derived from the bark of the cinchona tree and was the first highly effective anti-malarial drug; and the plant alkaloid morphine, which revolutionized the treatment of pain.

These pharmaceuticals are still in use today. A more recent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol. The discovery of taxol came about through collaborative work involving scientists at the National Cancer Institute within NIH and plant biologists at the U.S. Department of Agriculture. The plant biologists collected a wide diversity of plant materials, which were then evaluated for anti-carcinogenic properties. It was found that the bark of the Pacific yew tree yielded one such compound, which was eventually isolated and named taxol after the tree’s Latin name, *Taxus brevifolia*. Originally, taxol could only be obtained from the tree bark itself, but basic research led to identification of its molecular structure and eventually to its chemical synthesis in the laboratory.

On the basis of a growing understanding of metabolic networks, plants will continue to be sources for the development of new medicines to help treat cancer and other ailments. Taxol is just one example of a plant secondary compound. Since plants produce an estimated 200,000 such compounds, they will continue to provide a fruitful source of new drug leads, particularly if collaborations such as the one described above can be fostered and funded. With additional research support, plant biologists can lead the way to developing new medicines and biomedical applications to enhance the treatment of devastating diseases.

#### **Conclusion**

Despite the fact that plant biology research underlies so many vital practical considerations for our country, the amount invested in understanding the basic function and mechanisms of plants is small when compared with the impacts of this information on multibillion dollar sectors of the economy such as health, energy, and agriculture.

Clearly, the NIH does recognize that plants are a vital component of its mission. However, because the boundaries of plant biology research are permeable and because information about plants integrates with many different disciplines that are highly relevant to NIH, *ASPB hopes that the Subcommittee will provide additional resources through increased funding to NIH for plant biology in order to help pioneer new discoveries and new methods in biomedical research.*

Thank you for your consideration of our testimony on behalf of the American Society of Plant Biologists. Please do not hesitate to contact the American Society of Plant Biologists if we can be of any assistance in the future. For more information about the American Society of Plant Biologists, please see [www.aspb.org](http://www.aspb.org).

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American Society of Plant Biologists  
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## AMERICANS FOR NURSING SHORTAGE RELIEF

### Testimony of the Americans for Nursing Shortage Relief (ANSR) Alliance Regarding FY 2010 Appropriations for Nursing Workforce Development Programs

Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives

May 1, 2009

The undersigned organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony on FY 2010 appropriations for Title VIII – Nursing Workforce Development Programs. The Alliance represents a diverse cross-section of health care and other related organizations, health care providers, and supporters of nursing issues that have united to address the national nursing shortage. We stand ready to work with the 111<sup>th</sup> Congress to advance programs and policies that will ensure that our nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century. The Alliance, therefore, urges Congress to:

- **Appropriate \$215 million in funding in FY 2010 for the Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA).**
- **Fund the Advanced Education Nursing program (Sec. 811) at an increased level on par with the other Title VIII programs.**

#### The Extent of the Nursing Shortage

Nursing is the largest health care profession in the United States. According to the National Council of State Boards of Nursing, there were nearly 3.4 million licensed registered nurses (RNs) in 2006.<sup>1</sup> Nurses and advanced practice nurses (nurse practitioners, nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists) work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, and hospitals. Approximately 59 percent of RN jobs are in hospitals.<sup>2</sup> A federal report published in 2004 estimates that by 2020 the national nurse shortage will increase to more than 1 million full-time nurse positions. According to these projections, which are based on the current rate of nurses entering the profession, only 64 percent of projected demand will be met.<sup>3</sup> A study, published in March 2008, uses different assumptions to calculate an adjusted projected demand of 500,000 full-time equivalent registered nurses by 2025.<sup>4</sup> According to the U.S. Bureau of Labor Statistics, about 233,000 additional jobs for registered nurses will open

<sup>1</sup> National Council of State Boards of Nursing. (2008). *2006 Nurse License Volume and NCLEX® Examination Statistics. (Research Brief Vol. 31)*. On the Internet at: [https://www.ncsbn.org/08\\_2006\\_LicExamRB\\_Vol31\\_21208\\_MW\(1\).pdf](https://www.ncsbn.org/08_2006_LicExamRB_Vol31_21208_MW(1).pdf). (Accessed February 3, 2009).

<sup>2</sup> Bureau of Labor Statistics, U.S. Department of Labor. *Occupational Outlook Handbook, 2008-2009 Edition*, Registered Nurses. On the Internet at: <http://www.bls.gov/oco/ocos083.htm>. (Accessed December 9, 2008).

<sup>3</sup> Health Resources and Services Administration. (2004) *What is Behind HRSA's Projected Supply, Demand, and Shortage of Registered Nurses?* On the Internet at: <http://bhpr.hrsa.gov/healthworkforce/reports/behindmprojections/4.htm>. (Accessed December 9, 2008).

<sup>4</sup> Buerhaus, P., Staiger, D., Auerbach, D. (2008). *The Future of the Nursing Workforce in the United States: Data, Trends, and Implications*. Boston, MA: Jones & Bartlett.

each year through 2016, in addition to about 2.5 million existing positions. Based on these scenarios, the shortage presents an extremely serious challenge in the delivery of high quality, cost effective services, as the nation looks to reform the current healthcare system. Even considering only the smaller projection of vacancies, this shortage still results in a critical gap in nursing service, essentially three times the 2001 nursing shortage.

#### **Building the Capacity of Nursing Education Programs**

Nursing vacancies exist throughout the entire health care system, including long-term care, home care and public health. Even the Department of Veterans Affairs, the largest sole employer of RNs in the U.S., has a nursing vacancy rate of 10 percent. In 2006, the American Hospital Association reported that hospitals needed 116,000 more RNs to fill immediate vacancies, and that this 8.1 percent vacancy rate affects hospitals' ability to provide patient/client care.<sup>5</sup> Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase. Consequently, more must be done today by the government to help ensure an adequate nursing workforce for the patients/clients of today and tomorrow.

A particular focus on securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in – and qualified for – nursing school can matriculate in the year they are accepted. In the 2006-2007 academic years, 99,000 qualified applications – or almost 40 percent of qualified applications submitted to prelicensure RN programs – were denied due to lack of capacity.<sup>6</sup> Aside from having a limited number of faculty, nursing programs struggle to provide space for clinical laboratories and to secure a sufficient number of clinical training sites at health care facilities.

ANSR supports the need for sustained attention on the efficacy and performance of existing and proposed programs to improve nursing practices and strengthen the nursing workforce. The support of research and evaluation studies that test models of nursing practice and workforce development is integral to advancing health care for all in America. Investments in research and evaluation studies have a direct effect on the caliber of nursing care. Our collective goal of improving the quality of patient/client care, reducing costs, and efficiently delivering appropriate health care to those in need is served best by aggressive nursing research and performance and impact evaluation at the program level.

#### **The Impact on the Nation's Public Health Infrastructure**

The National Center for Health Workforce Analysis reports that the nursing shortage challenges the health care sector to meet current service needs. Nurses make a difference in the lives of patients/clients from disease prevention and management to education to responding to emergencies. Chronic diseases, such as heart disease, stroke, cancer, and diabetes, are the most preventable of all

<sup>5</sup>American Hospital Association, (2007) *The State of America's Hospitals: Taking the Pulse, Findings from the 2007 AHA Survey of Hospital Leader*. On the Internet at: <http://www.aha.org/aha/content/2007/PowerPoint/StateofHospitalsChartPack2007.ppt>. (Accessed December 3, 2008).

<sup>6</sup>National League for Nursing, (2009) *Nursing Data Review 2006-2007: Baccalaureate, Associate Degree, and Diploma Programs*. On the Internet at: <http://www.nln.org/research/slides/index.htm>. (Accessed March 20, 2009).

health problems as well as the most costly. Nearly half of Americans suffer from one or more chronic conditions and chronic disease accounts for 70 percent of all deaths. In addition, increased rates of obesity and chronic disease are the primary cause of disability and diminished quality of life.

Even though America spends more than \$2 trillion annually on health care – more than any other nation in the world – tens of millions of Americans suffer every day from preventable diseases such as type 2 diabetes, heart disease, and some forms of cancer that rob them of their health and quality of life.<sup>7</sup> In addition, major vulnerabilities remain in our emergency preparedness to respond to natural, technological and manmade hazards. An October 2008 report issued by Trust for America's Health entitled "Blueprint for a Healthier America" found that the health and safety of Americans depends on the next generation of professionals in public health.<sup>8</sup> Further, existing efforts to recruit and retain the public health workforce are insufficient. New policies and incentives must be created to make public service careers in public health an attractive professional path, especially for the emerging workforce and those changing careers.

An Institute of Medicine report notes that nursing shortages in U.S. hospitals continue to disrupt hospitals operations and are detrimental to patient/client care and safety.<sup>9</sup> Hospitals and other health care facilities across the country are vulnerable to mass casualty incidents themselves and/or in emergency and disaster preparedness situations. As in the public health sector, a mass casualty incident occurs as a result of an event where sudden and high patient/client volume exceeds the facilities/sites resources. Such events may include the more commonly realized multi-car pile-ups, train crashes, hazardous material exposure in a building or within a community, high occupancy catastrophic fires, or the extraordinary events such as pandemics, weather-related disasters, and intentional catastrophic acts of violence.

Since 80 percent of disaster victims present at the emergency department, nurses as first receivers are an important aspect of the public health system as well as the healthcare system in general. The nursing shortage has a significant adverse impact on the ability of communities to respond to health emergencies, including natural, technological and manmade hazards.

### **Summary**

The link between health care and our nation's economic security and global competitiveness is undeniable. Having a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to reforming the health care system as well as improving the health status of the nation and reducing health care costs. To mitigate the immediate effect of the nursing shortage and to address all of these policy areas, **ANSR requests \$215 million in funding for the Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at HRSA in FY 2010. As part of this funding, the Advanced Education Nursing training program (Sec. 811) should be funded at an increased level on par with the other Title VIII programs.**

<sup>7</sup> KaiserEDU.org. "U.S. Health Care Costs: Background Brief." Kaiser Family Foundation. On the Internet at: [http://www.kaiseredu.org/topics\\_im.asp?imID=1&parentID=61&id=358](http://www.kaiseredu.org/topics_im.asp?imID=1&parentID=61&id=358) (Accessed November 24, 2008).

<sup>8</sup> Trust for America's Health. (2008) *Blueprint for a Healthier America: Modernizing the Federal Public Health System to Focus on Prevention and Preparedness*. On the Internet at: <http://healthyamericans.org/report/55/blueprint-for-healthier-america> (Accessed December 3, 2008).

<sup>9</sup> Institute of Medicine, Committee on the Future of Emergency Care in the United States Health System. (2007) *Hospital-Based Emergency Care: At the Breaking Point*. On the Internet at: <http://www.iom.edu/?id=48896>. (Accessed December 3, 2008).

Academy of Medical-Surgical Nurses	National Association of Clinical Nurse Specialists
American Academy of Ambulatory Care Nursing	National Association of Neonatal Nurses
American Academy of Nurse Practitioners	National Association of Neonatal Nurse Practitioners
American Academy of Nursing	National Association of Nurse Massage Therapists
American Association of Critical-Care Nurses	National Association of Nurse Practitioners in Women's Health
American Association of Nurse Anesthetists	National Association of Orthopaedic Nurses
American Association of Nurse Assessment Coordinators	National Association of Pediatric Nurse Practitioners
American Association of Nurse Executives	National Association of Registered Nurse First Assistants
American Association of Occupational Health Nurses	National Black Nurses Association
American College of Nurse Practitioners	National Council of State Boards of Nursing
American Organization of Nurse Executives	National Gerontological Nursing Association
American Psychiatric Nurses Association	National League for Nursing
American Society for Pain Management Nursing	National Nursing Centers Consortium
American Society of PeriAnesthesia Nurses	National Nursing Staff Development Organization
American Society of Plastic Surgical Nurses	National Organization for Associate Degree Nursing
Association for Radiologic & Imaging Nursing	National Organization of Nurse Practitioner Faculties
Association of Pediatric Hematology/Oncology Nurses	National Student Nurses' Association, Inc.
Association of periOperative Registered Nurses	Nurses Organization of Veterans Affairs
Association of Rehabilitation Nurses	Oncology Nursing Society
Association of State and Territorial Directors of Nursing	Pediatric Endocrinology Nursing Society
Association of Women's Health, Obstetric & Neonatal Nurses	RN First Assistants Policy & Advocacy Coalition
Developmental Disabilities Nurses Association	Society of Gastroenterology Nurses and Associates, Inc.
Emergency Nurses Association	Society of Pediatric Nurses
Gerontological Advanced Practice Nurses Association	Society of Trauma Nurses
Infusion Nurses Society	Wound, Ostomy and Continence Nurses Society
International Society of Nurses in Genetics, Inc.	
Legislative Coalition of Virginia Nurses	

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## Animal Welfare Institute

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### TESTIMONY

Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
 of the House of Representatives Committee on Appropriations  
 for FY 2010

By Cathy Liss, President  
 May 1, 2009

The Animal Welfare Institute (AWI) respectfully requests that the Subcommittee include the following report language regarding the funding of research involving the use of dogs and/or cats:

*None of these funds shall be used for the purchase of, or research on, dogs or cats obtained from those USDA licensed Class B dealers who acquire dogs or cats from third parties (i.e. individuals, dealers, breeders and animal pounds) and resell them.*

In response to the request included in last year's appropriation bill, the National Academy of Sciences (NAS) established a committee in the summer of 2008 to assess if there is a scientific rationale for relying on dogs and cats obtained from United States Department of Agriculture (USDA) licensed Class B dealers. Information on the Committee on Scientific and Humane Issues in the Use of Random-source Dogs and Cats for Research (ILAR-K-08-01-A) can be found at: <http://www8.nationalacademies.org/cp/projectview.aspx?key=48974>. The results of its deliberations are expected to be public later this month.

Based on our review of the data submitted to the NAS Committee, the presentations given during those portions of the meetings that were open to public, and our own extensive experience regarding Class B licensed dealers, we anticipate findings in keeping with the proposed report language above.

According to USDA, of the nearly 95,000 total dogs and cats used in research, 2,863 dogs and 267 cats were supplied by random source dealers during FY 2007. There are a mere 10 Class B dealers currently licensed by USDA and selling live random source dogs and cats for experimentation. One other dealer is presently under a 5-year license suspension. These dealers are notorious for selling to laboratories animals who have been acquired illegally and for their widespread failure to comply with other minimum requirements under the Animal Welfare Act. In fact, at this time, half of the remaining 10 dealers are under investigation by USDA for apparent violations of the Animal Welfare Act (AWA), and USDA is pursuing 7 separate investigations regarding apparent supply violations identified during tracebacks conducted of dealer records.

Data from USDA inspection reports reveal myriad problems with licensed Class B dealers (we can supply copies of these inspection reports if they are of interest): Needed veterinary care is lacking for many random source animals. Hookworm and mange are a widespread problem as is heartworm, particularly in the South. An Ohio dealer had a dog with mange on his head, around the eyes, ears and neck. Another dog had enlarged pupils and bulging eyes, and a third had dried loose dark stool. An Indiana dealer was cited by USDA for dogs suffering from “loose stool with some blood,” “loose stool with a drop of blood,” “infected or irritated eye,” “mange-like lesions,” “ring-worm like lesions,” “sore on left carpus which was red and warm to the touch,” and an animal with “a bite wound to the right front foot.” At another inspection, this dealer had two animals who were limping; one had a large tumor on his foot. A third animal had a bite laceration on his face. Another record notes a chronic cough in an underweight dog and a dog with a purulent discharge from his nose. In most cases there is no record of any veterinary care, and after being cited by USDA inspectors, given the poor status of the animals, they are typically killed. An Illinois dealer was cited by USDA for “euthanizing dogs with truck exhaust and tying sick dogs out at the corner of the property where they would die.” Later he shifted to use of an electric current administered via clips.

Research institutions may reject animals delivered by a dealer because of the poor condition of the dogs and cats, leaving them to be hauled from location to location in search of a taker. If not, the animal may be taken back and left to die or may simply be shot. Some at research institutions have let USDA know of their concerns. One such email identified a cat “in very poor condition: cache[c]tic, severely matted hair coat and a severe case of ear mites.” It went on to note: “Many of the cats that we receive are wild or are almost wild. I do not understand where these cats come from and how they are examined for health certificates. I thought the animals had to come from someone who had raised and bred the animals on their property or from a specific shelter.”

The conditions for housing, feeding, and care can be problematic as well. An Ohio dealer was cited by USDA inspectors for contaminated straw, wet with urine and excessive feces. Excessive flies. Water receptacles contaminated with black and green algae—a thick layer. A dealer in Indiana had dogs unable to avoid contact with excreta. Another dealer’s inspection report notes, “Some 70-75% dogs have water and bread and little bits of dog food floating in water. There were some dogs that had only bread and water. Some had dog food floating in water. Most of dogs had not eaten the watery food blend....About 70% of the total dogs had non-potable water. Water was mixed with bread and dog food and sitting in the direct sun.”

In addition, there are widespread problems with record-keeping and acquiring animals from illegal sources. Further, dealers commonly network with each other; that is, animals are sold from buncher (an unlicensed dealer) to dealer to another dealer before being sold for research. Also, typically, the buncher is immune from prosecution until he is caught by USDA and warned not to sell more than 25 animals in a year without a license again. Then he drops down to selling fewer animals so he is exempt from licensure, he sells some of the animals using the name of someone else he knows, OR he steps forward and gets licensed for a while, makes a lot of money and then when USDA appears to be catching up with him, he turns in his license.

One example is the case of Clayton McDowell, a buncher with hunting dog kennels who didn't let the fact that he had no license stop him from selling 60 dogs to a USDA licensed Class B dealer in Illinois. According to USDA, he "knew about USDA licensing requirements. He stated he would quit selling dogs to B dealers. He stated there was too much hassle with identification, record keeping." McDowell received a Letter of Warning from USDA, and he addressed the matter by getting licensed. Ultimately he decided to quit operating as a licensed Class B dealer, though he continued selling hunting dogs, claiming he would only sell the dogs retail for hunting purposes.

Then there's a Kentucky dealer cited by a USDA inspector who repeatedly failed to include essential details on the acquisition sheets, such as the seller's address, driver's license number, and vehicle tag number. He was found to have failed to collect this information on three different dates regarding 13 animals. And a Michigan dealer was cited for receiving stray cats from the city of Howard City. The city has no pound, but the licensed dealer was willing to step in and collect cats. An Illinois dealer was cited on at least three separate occasions for his failure to maintain complete records.

A veterinarian at a research facility expressed concern in an email to USDA that the animals it received from a dealer appeared to be "companion animals." A neutered male Airedale, an intact male Weimeriner and a male chocolate Labrador all were affectionate and obeyed commands. Similarly, the cats received by the facility were "some of the most obedient and affectionate cats that we ever met."

Another common pattern is for individuals to pass the business on to other members of the family after carefully showing them the ropes. Sometimes a former employee of a dealer, who has also learned how to work the system, may go off on his own and get licensed as well. Though it's not a formal program, in essence some dealers offer an apprenticeship.

Brothers living in MO ran their licensed Class B dealer operation as a team, then one of them retired and the other's wife joined him in running the business. USDA finally caught up with the pair, and they were charged with a laundry list of violations, including failure to maintain records that fully and correctly disclose the identities and other required information of the persons from whom dogs were acquired on 51 separate occasions, including one incident that pertained to 43 dogs. Further, they were charged with failing to provide complete certifications on seven separate occasions, including one that pertained to 195 dogs. The husband died before the case was resolved and though the wife was fined \$107,250, the judge suspended \$100,000 of it. The story doesn't end here. The couple's son and daughter-in-law, after helping mom close down her business, set up their own Class B dealer operation.

During a House Agriculture Subcommittee hearing held back in 1996, then Assistant Secretary of Agriculture Michael Dunn described his frustration with random source dealers: "Every time we develop a new way to look for something, they develop a new way to hide it." An insurmountable hurdle for USDA is that the AWA allows anyone who *claims* to have bred and raised an animal to profit by selling the animal to a random source dealer—and how can USDA be expected to disprove it? In addition, with animals transported back and forth across the country, how on earth is USDA supposed to keep up with the movement of animals? USDA has spent years inspecting random source dealers four times a year instead of once a year as is done with all other licensees and registrants under the AWA. In the meantime, unlike any other

licensees covered under the AWA, this one group of licensees—Class B dealers selling dogs and cats for research—have a long-standing problem maintaining complete and accurate records.

The Animal Welfare Act was passed in 1966 to address the illegal supply of dogs and cats to laboratories, and here we are 43 years later, and these problems are still widespread. What has changed significantly over this lengthy period of time is the availability of animals from sources other than random source dealers. Given the problems inherent in the use of licensed Class B dealers, researchers have increasingly and successfully shifted to acquiring most of their dogs and cats from licensed Class A breeders—and by using these dealers instead, the researchers will receive animals who have been raised under controlled conditions, and the health and vaccination status and the genetic background on each individual animal will be known. In addition, some dogs and cats are being bred for experimentation at registered research facilities, and in some cases, inexpensive random type animals are purchased directly from animal pounds.

NIH has told this Subcommittee that it is “committed to ensuring the appropriate care and use of animals in research.” However, NIH has left the decision of whether or not to buy dogs and cats from random source dealers “to the local level on the basis of scientific need.” NIH defends the use of licensed Class B dealers, arguing that these dealers are needed to obtain “animals that may not be available from other sources, such as genetically diverse, older, or larger animals.” In fact, in the rare circumstance that a researcher asserts the need for such animals, they can be obtained directly from pounds, as noted previously.

The distinction between non-purpose-bred animals from pounds versus licensed Class B dealers must be made. By using licensed Class B dealers (middlemen) instead of pounds, researchers are contributing to the problem. In their search to fill researchers’ demands for “genetically diverse, older or larger animals,” random source dealers and their suppliers may be stealing pets from backyards and farms or they may be acquiring them from individuals who did not breed and raise them as required by the AWA.

All animals used in research should be obtained from lawful sources. Taxpayer dollars, in the form of NIH extramural grants, must not continue to fund research using dogs and cats from dealers whose *modus operandi* is illegal acquisition of animals, fraudulent or incomplete records, and other illicit activities. Proper oversight of NIH’s dispersal of extramural grants to those engaged in research using dogs and/or cats is urgently needed.

Thank you very much for your consideration of our request for report language to address this issue.

**Testimony before the House Appropriations Subcommittee on Labor,  
Health and Human Services, and Education**

**By  
Neil Horikoshi, President & Executive Director  
Asian & Pacific Islander American Scholarship Fund  
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Thank you, Mr. Chairman and members of the subcommittee, for giving me the opportunity to testify on the educational concerns and needs of the Asian and Pacific Islander American (APIA) community.

The Asian & Pacific Islander American Scholarship Fund (APIASF) is the nation's largest 501(c)3 non-profit organization that provides scholarships to Asian and Pacific Islander Americans (APIAs) with financial need. Our goal is to not only provide the critical access to higher education to APIA students, but to make sure that all APIA students have the resources to cultivate their academic, personal and professional success.

Everyday we face the challenges of being considered the "model" minority. People believe that APIA students naturally excel academically and that our students do not need extra support to obtain their true potential. It is well documented that many APIA groups have educational levels that are below the national average, with several ranking among the lowest in the nation.

According to a study of the 2000 Census data conducted by the Southeast Asian Resource Action Center, only 26 percent of Laotian and 28 percent of Cambodian Americans have had some college education compared to the national average of 51.8 percent. That study also found that 45 percent of Hmong Americans indicated that they had no formal schooling compared to 1.4 percent nationally.

In fact, 84 percent of our APIASF general scholarship recipients are the first in their families to attend college and 60 percent come from families earning less than \$25,000 a year. The majority of our students, like most APIA students, attend public institutions.

Unfortunately, the challenges facing APIA students don't end when they arrive on campus.

Studies show that APIA students are often marginalized and overlooked in leadership development programs on campuses. Additionally, APIA students may not readily relate to or embrace the label of "leader" relative to their White peers.

Many APIA students struggle with the anxiety associated with being the "model minority" and the expectations of academic success. Studies of students at highly selective four-year institutions show that Asian American and Pacific Islander students exhibit the lowest self-efficacy and self-esteem of any student group.

The APIA population is one of the fastest growing segments of the population in the U.S. and the challenges facing our students are only going to continue to grow.

By enacting the Asian American and Native American Pacific Islander Serving Institutions (AANAPISI) program, Congress made a significant step in recognizing the needs that exist within the diverse APIA population. However, this action will be fruitless if this vital program is not fully funded.

I urge the Labor, Health and Human Services, and Education Subcommittee to provide the \$30 million dollars of funding for FY 2010 so this program can help thousands of deserving APIA students overcome the barriers keeping them from a college degree and help better serve APIA students on campus.

Fully funding the AANAPISI program will allow institutions serving a significant number of low income APIA students to strengthen curriculum, renovate classrooms, work with community based organizations, develop outreach programs for elementary and high school students, and conduct research and collect data on Asian and Pacific Islander American populations.

Investing in education and in the Asian and Pacific Islander American community will contribute to the success of future generations and to a stronger America.

Thank you, again Mr. Chairman and members of the subcommittee for the opportunity to share with you the importance of the Asian American and Native American Pacific Islander Serving Institutions (AANAPISI) program.

TESTIMONY  
on the  
FY 2010 BUDGET  
of the  
NATIONAL INSTITUTES OF HEALTH  
before the  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION  
COMMITTEE ON APPROPRIATIONS  
UNITED STATES HOUSE OF REPRESENTATIVES  
  
THE HONORABLE DAVID OBEY, CHAIR  
April 30, 2009

**Organization:** ASSOCIATION FOR PSYCHOLOGICAL SCIENCE  
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SUMMARY OF RECOMMENDATIONS

- As a member of the Ad Hoc Group for Medical Research Funding, **APS recommends \$32.4 billion for NIH in FY 2010.**
- **APS requests Committee support for behavioral and social science research and training as a core priority at NIH** in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.
- Given the critical role of basic behavioral science research and training in addressing many of the Nation's most pressing public health needs, **we ask the Committee to ensure that NIH leadership carries out its plan to create a cross-NIH basic behavioral research funding initiative, and coordinates with all Institutes and Centers to provide support for basic behavioral science research.**
- **APS encourages the Committee to support behavioral science priorities at individual institutes.** Examples are provided in this testimony to illustrate the exciting and important behavioral and social science work being supported at NIH.

**Mr. Chairman, Members of the Committee:** My name is Dr. Amy Pollick, and I am speaking on behalf of the Association for Psychological Science. Thank you for the opportunity to provide this statement on the FY 2010 appropriations for the National Institutes of Health. As our organization's name indicates, APS is dedicated to all areas of scientific psychology, in research, application, teaching, and the improvement of human welfare. Our 21,000 members are scientists and educators at the Nation's universities and colleges, conducting NIH-supported basic and applied, theoretical and clinical research. They look at such things as: the connections

between emotion, stress, and biology and the impact of stress on health; they look at how children grow, learn, and develop; they use brain imaging to explore thinking and memory and other aspects of cognition; they develop ways to manage debilitating chronic conditions such as diabetes and arthritis as well as depression and other mental disorders; they look at how genes and the environment influence behavioral traits such as aggression and anxiety; and they address the behavioral aspects of smoking and drug and alcohol abuse.

As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$32.4 billion for NIH in FY 2010, an increase of 7% over the FY 2009 appropriations level. This increase would halt the erosion of the Nation's public health research enterprise, and help restore momentum to our efforts to improve the health and quality of life of all Americans.

Within the NIH budget, APS is particularly focused on behavioral and social science research and the central role of behavior in health. The remainder of my testimony concerns the status of those areas of research at NIH.

#### **HEALTH AND BEHAVIOR: THE CRITICAL ROLE OF BASIC AND APPLIED PSYCHOLOGICAL RESEARCH**

Behavior is a central part of health. Many leading health conditions – such as heart disease; stroke; lung disease and certain cancers; obesity; AIDS; suicide; teen pregnancy; drug abuse and addiction; depression and other mental illnesses; neurological disorders; alcoholism; violence; injuries and accidents – originate in behavior and can be prevented or controlled through behavior.

As just one example: stress is something we all feel in our daily lives, and we now have a growing body of research that illustrates the direct link between stress and health problems:

- Chronic stress accelerates not only the size but also the strength of cancer tumors;
- chronic stressors weaken the immune system to the point where the heart is damaged, paving the way for cardiac disease;
- children who are genetically vulnerable to anxiety and who are raised by stressed parents are more likely to experience greater levels of anxiety and stress later in life;
- animal research has shown that stress interferes with working memory; and
- stressful interactions may contribute to systemic inflammation in older adults, which in turn extends negative emotion and pain over time.

None of the conditions or diseases described above can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating, and preventing them. Just as there exists a layered understanding, from basic to applied, of how molecules affect brain cancer, there is a similar spectrum for behavioral research. For example, before you address how to change attitudes and behaviors around AIDS, you need to know how attitudes develop and change in the first place. Or, to design targeted therapies for bipolar disorder, you need to know how to understand how circadian rhythms work as disruptions in sleeping patterns have been shown to worsen symptoms in bipolar patients.

#### **Basic Behavioral Science Research Needs a Stable Infrastructure**

Broadly defined, behavioral research explores and explains the psychological, physiological, and environmental mechanisms involved in functions such as memory, learning, emotion, language, perception, personality, motivation, social attachments, and attitudes. Within



this, *basic* behavioral research aims to understand the fundamental nature of these processes in their own right, which provides the foundation for *applied* behavioral research that connects this knowledge to real-world concerns such as disease, health, and life stages. Basic behavioral research continues to fare poorly at NIH, a circumstance that jeopardizes the success of the entire behavioral research enterprise. Let me remind you of the current situation:

Traditionally, the National Institute of Mental Health (NIMH) was the home for far more basic behavioral science than any other institute. Many basic behavioral and social questions were being supported by NIMH, even if their answers could also be applied to other institutes. But NIMH has reduced its support for many areas of the most basic behavioral research, in favor of translational and clinical research. This means that previously funded areas now are not being supported.

NIMH's abrupt decision to narrow its portfolio came without adequate planning and happened at the expense of critical basic behavioral research. We favor a broader spectrum of support for basic behavioral science across NIH as appropriate and necessary for a vital research enterprise. But until other Institutes have the capacity to support more basic behavioral science connected to their missions, programs of research in fundamental behavioral phenomena such as cognition, emotion, psychopathology, perception, and development, will continue to languish.

Current NIH leadership recognizes this gap, and has asked the Directors of the National Institute of General Medical Sciences and the National Institute of Aging to co-lead a new initiative that supports and expands new basic behavioral research throughout NIH. In March 2009, NIH leadership confirmed its commitment to this Basic Behavioral Research Opportunity Network in testimony to this Subcommittee, and APS asks you to ensure that NIH follows through with the planning and execution of this crucial step forward for basic behavioral science at NIH and ultimately the health of all Americans.

Despite the clear central role of behavior in health, behavioral research has not received the recognition or support needed to prevent, or reverse the effects of, behavior-based health problems in this Nation. APS asks that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, by encouraging NIH to advance a model of health that includes behavior in its scientific priorities, and by encouraging stable support for basic behavioral science research at NIH.

#### BEHAVIORAL SCIENCE AT KEY INSTITUTES

In the remainder of my testimony, I would like to highlight examples of cutting-edge behavioral science research being supported by individual institutes.

**National Cancer Institute (NCI):** NCI's Behavioral Research Program continues to make excellent progress, supporting basic behavioral research as well as translational research on the development and dissemination of interventions in areas such as tobacco use, dietary behavior, sun protection, and decision-making. Recently, NCI's behavioral research branch has made concerted efforts to incorporate innovative social psychological theories into cancer prevention research. Basic social psychology provides useful and practical approaches for understanding risky health behaviors and tailoring interventions to reduce the incidence of cancer. For example, NCI funded a research program to assess differential psychological and physiological responses to exercise and the possible genetic and biological mechanisms of those responses. As a result, we now understand the influence of responses to cardiovascular exercise on future

exercise behavior, and the researchers are evaluating an intervention to increase exercise behavior in sedentary participants. It is this kind of basic behavioral research that helps us understand how people are persuaded to adopt and maintain healthy behaviors. APS asks Congress to support NCI's behavioral science research and training initiatives and to encourage other Institutes to use these programs as models.

**National Institute on Aging (NIA):** NIA's Division of Behavioral and Social Research has one of the strongest psychological science portfolios in all of NIH, and is supporting wide-ranging and innovative work. For example, normal aging may be accompanied by declines not only in such cognitive functions, but also in the processes supporting social and emotional behavior. However, we currently know little about the changes that may occur as we age. NIA-supported research into the brain mechanisms and cognitive processes underlying social and emotional behaviors in healthy older adults promises to dramatically increase our knowledge in this area. Using a combination of behavioral and neuroimaging methods to study social and emotional processing in normal aging, this research will lead to much greater understanding of the nature of aging-related changes in these central human characteristics. NIA's commitment to cutting-edge behavioral science is further illustrated by the Institute's leadership role in NIH's new initiative on the Science of Behavior Change. APS asks the Committee to support NIA's behavioral science research efforts and to increase NIA's budget in proportion to the overall increase at NIH in order to continue its high quality research to improve the health and wellbeing of older Americans.

**National Institute on Drug Abuse (NIDA):** By supporting a comprehensive research portfolio that stretches across behavior, neuroscience, and genetics, NIDA is leading the Nation to a better understanding of drug abuse which is key to both prevention and treatment. One of the striking things about psychological science research is that it often dispels "common sense" intuition. For example, recent NIDA-supported research has shown that certain anti-drug media campaigns that include attention-grabbing features such as harsh content or strong graphics, have no positive effect, and that in fact the campaigns that use *fewer* such dramatic features actually lead to better processing of the public service announcement (PSA). This kind of message-framing research will be used to develop and tailor the most effective PSAs, such as those that focus on social risk rather than physical damage, to curtail use of a wide variety of illicit substances. NIDA is also encouraging brain imaging and prevention message investigators to work together, fostering increased validation of health communication models. APS asks the Committee to support this and other critical behavioral science research at NIDA, and to increase NIDA's budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

**Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD):** Several Institutes recognize the value and relevance of basic behavioral research to their mission, and NICHD is to be particularly commended for its support of behavioral research on important topics such as mechanisms of cognition and learning, developmental trajectories of language, and linkages among brain, behavior, and genes. For example, studies have shown that caregiver behavior can modify genetic influences on social behavior. Children with a particular variation of the serotonin gene who live in families that provide low levels of social and emotional support were found to be at increased risk for extreme shyness and social withdrawal in middle school years. But those children whose families provide high levels of support, and

who have that same genetic variation, didn't show the same levels of shyness. Research supported by NICHD's behavioral science programs continues to yield fundamental new insights into understanding early cognitive and behavioral development that have the potential to change how and when medical and psychological specialists evaluate typical cognitive, social, and behavioral development during infancy. APS asks Congress to support NICHD's sustained behavioral science research portfolio and to encourage other Institutes to partner with NICHD to maximize the development of interventions in early stages of life that have invaluable benefits in adulthood.

It's not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those reviewed in this statement, many other institutes play a key role in the NIH behavioral science research enterprise. These include the National Institute of Dental and Craniofacial Research, the National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism, the National Heart, Lung, and Blood Institute, the National Institute of Diabetes and Digestive and Kidney Diseases, and the National Institute on Neurological Diseases and Stroke. Behavioral science is a central part of the mission of these institutes, and their behavioral science programs deserve the Committee's strongest possible support.

This concludes my testimony. Again, thank you for the opportunity to discuss NIH appropriations for FY 2010 and specifically, the importance of behavioral science research in addressing the Nation's public health concerns. I would be pleased to answer any questions or provide additional information.

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[About ARVO appears on last page.]

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**April 24, 2009**

ARVO Written Testimony in Support of Increased FY10 Funding for the  
National Institutes of Health (NIH) and the National Eye Institute (NEI)  
[Submitted on behalf of the ARVO President, Todd Margolis, MD, PhD]

House Committee on Appropriations Subcommittee on  
Labor, Health & Human Services, Education, and Related Agencies

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ARVO has two major requests:

- 1) **For Congress to fund NIH in FY2010 at \$32.4 billion** (a seven percent increase over FY2009);
- 2) **For Congress to make vision health a priority in the total funding of NIH** by increasing NEI funding to \$736 million (also a seven percent increase over FY2009).

The requested seven percent increase for NIH and NEI budgets represents a three percent increase plus the 2009 biomedical inflation index.

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ARVO commends Congress for actions taken in FY2008 and 2009 to fund NIH. This includes the \$150 million FY2008 supplement for investigator-initiated grants, the \$10.4 billion of NIH funding included in the American Recovery and Reinvestment Act (ARRA), and the FY2009 inflationary increase of 3.2 percent. However, ARVO still has concerns about long-term, sustained and predictable funding for vision research.

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Vision disorders are the fourth most prevalent disability in the US and the most frequent cause of disability in children.<sup>1-4</sup> Vision impacts fundamental life activities including the ability to learn, communicate and work. Healthy vision contributes to injury prevention, independence, and economic security. Over the next 30 years the elderly population of the US is expected to double, and if we do not take active steps to maintain ocular health in this population, age-related eye diseases (diabetic retinopathy, glaucoma, cataracts, and age-related macular degeneration) will quickly over-burden our healthcare system. While age-related eye diseases are the most common visual impairments in the US, childhood vision loss is also of great concern because of its lifelong impact and long-term economic burden.

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ARVO requests \$32.4 billion of NIH funding for FY2010. This represents a seven percent increase over FY2009.

- *To ensure that prior investments in training junior investigators and clinician scientists translate to future improvements in health and health care services.*

**If junior investigators are unable to obtain research grants from the NIH, then the prior government investment in their training will not translate into future translational medical breakthroughs. These well trained scientists will simply transfer acquired skills to other career options.<sup>5</sup>**

During the 1980s and 1990s our universities saw an exponential increase in the number of post-doctoral trainees, while the number of academic positions declined.<sup>5</sup> This was followed by a doubling of the NIH budget (1993-2003), when universities increased their infrastructure for training life science PhDs and hired more full-time faculty. NIH funding since remained flat, resulting in decreased rates of grant funding. As a consequence many academic scientists have either lost their jobs or moved to part-time positions.<sup>7</sup> The current worldwide economic crisis has further amplified the problem. In recent months, the private sector in the US laid off over 80,000 scientists.<sup>8</sup> All these factors put the US in danger of losing its investment in scientists who graduated after 2003. At the same time many senior scientists at academic institutions are finding it extremely difficult to maintain funding for their labs. We think the best solution is to maintain sustained and predictable funding for scientists at all stages. If the average age when scientists obtain their first source of independent NIH funding continues to rise (currently 43 years) and funding bodies continue to restrict many post-doctoral

funding opportunities to 2-5 years, a generation of analytical thinkers will be forced to find more realistic career options.<sup>9</sup>

- *To maintain economic and global competitiveness.*

**Research & development is essential for the US to remain competitive in a global market.** Both corporate and government support of research has been declining. Innovation is crucial for maintaining global competitiveness.<sup>10</sup> Since vision problems are a global economic concern, the prevention and treatment of ocular disease contributes to the economic well-being of the US and international economy

**NIH and NEI have been leaders in basic research that translates to better vision therapies.** The NEI Director (Paul Sieving, MD, PhD) has reported that 25% of all genes identified to date are associated with eye disease, and ongoing research supported by the NEI is aimed at translating these genetic discoveries to improved therapies for eye disease. The NEI has also been working in association with: 1) the National Institute on Aging to better diagnose, prevent, and treat age-related macular degeneration, diabetes, and cataract; 2) The National Institute of Neurological Disorders and Stroke to protect and regenerate cells that die from retinal degeneration and glaucoma; and 3) the National Institute of Diabetes and Digestive and Kidney Disorders on studies of diabetic retinopathy

NEI sponsored research has resulted in improved therapies for age-related macular degeneration and diabetic retinopathy, a promising gene therapy for retinitis pigmentosa, and genetic studies of glaucoma in minority populations that have a disproportional higher incidence of glaucoma (including African American and Hispanic populations).<sup>16</sup>

- *To reduce the economic burden of eye disease on the US health care system*

In 2008 there were 3,638,186 cases of blindness in the US. This number is expected to grow with the aging of the baby boomer population. One in 28 individuals over age 40 has a visual disability. In 2010 more than half of baby boomers will be at high risk for developing age-related eye diseases. Adequate research funding of studies aimed at preventing these age related diseases will reduce future health care expenditures, particularly to the Medicare and Medicaid programs.<sup>17-19</sup>

Treatment of eye diseases in the US costs \$68 billion/year. Vision impaired adults are employed at 44% the rate of healthy individuals and earn an average of \$10,000 less per year.<sup>20-22</sup> Vision science research leads to therapies that delay,

prevent and treat blinding ocular disease, leading to economic savings in the cost of health care, and increased productivity of our work force.

### Summary

*ARVO urges FY2010 NIH and NEI funding at \$32.4 billion and \$736 million, respectively, reflecting an at-least seven percent increase over FY2009.*

### References

1. Federal Interagency Forum on Aging-Related Statistics. Older Americans 2000: key indicators of well-being. Washington, DC: US Government Printing Office; 2000 Aug. 114 p.
2. <http://www.ncbi.nlm.nih.gov/pubmed/15078664>
3. <http://www.healthypeople.gov/data/2010prog/focus28/2004fa28.htm>
4. <http://www.preventblindness.org/vpus/>
5. <http://www.the-scientist.com/article/display/16526/>
6. [http://www.sauvonslarecherche.fr/IMG/pdf/the\\_postdoc\\_crisis.pdf](http://www.sauvonslarecherche.fr/IMG/pdf/the_postdoc_crisis.pdf)
7. [http://sciencecareers.sciencemag.org/career\\_magazine/previous\\_issues/articles/2007\\_07\\_13/caredit.a0700099](http://sciencecareers.sciencemag.org/career_magazine/previous_issues/articles/2007_07_13/caredit.a0700099)
8. [http://sciencecareers.sciencemag.org/career\\_magazine/previous\\_issues/articles/2009\\_04\\_10/caredit.a0900048](http://sciencecareers.sciencemag.org/career_magazine/previous_issues/articles/2009_04_10/caredit.a0900048)
9. <http://www.brokenpipeline.org/brokenpipeline.pdf>
10. <http://www.nsf.gov/statistics/nsb0803/start.htm#research>
11. <http://www.v2020.org/page.asp?section=000100010002>
12. <http://www.v2020resource.org/newsitenews.aspx?tpath=news22007>
13. <http://www.healthypeople.gov/HP2020/>
14. [http://www.nei.nih.gov/resources/strategicplans/neiplan/firm\\_cross.asp](http://www.nei.nih.gov/resources/strategicplans/neiplan/firm_cross.asp)
15. <http://www.nei.nih.gov/amd/>
16. [http://www.eyerresearch.org/resources/NEI\\_factsheet.html](http://www.eyerresearch.org/resources/NEI_factsheet.html) ARVO site?
17. [http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=pubmed&dopt=AbstractPlus&list\\_uids=15078664](http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=pubmed&dopt=AbstractPlus&list_uids=15078664)
18. <http://www.researchamerica.org/uploads/factsheet16vision.pdf>
19. [http://www.preventblindness.org/advocacy/Action\\_Plan.pdf](http://www.preventblindness.org/advocacy/Action_Plan.pdf)
20. <http://www.nei.nih.gov/>
21. [http://www.eyerresearch.org/pdf/RA\\_Vision\\_08\\_V5.pdf](http://www.eyerresearch.org/pdf/RA_Vision_08_V5.pdf)
22. <http://www.ncbi.nlm.nih.gov/sites/entrez>

**About ARVO**

ARVO is the world's largest international association of vision scientists (scientists who study diseases and disorders of the eye). About eighty percent of the United States members (>7,000 total) are supported by NIH grant funding. Vision science is a multi-disciplinary field, but the National Eye Institute is the only freestanding NIH institute with a mission statement that specifically addresses vision research. ARVO supports increased FY2010 NIH funding.

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**More Information**

To find out more, please contact Bobbie Ann Austin, PhD, ARVO Assistant Director of Science Program and Policy: [baustin@arvo.org](mailto:baustin@arvo.org) or 240-221-2901.

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Association of  
American Cancer Institutes

**Written Testimony to the United States House of Representatives  
Appropriations Committee, Subcommittee for  
Labor, Health and Human Services, Education and Related Agencies  
Regarding FY 2010 Cancer-Related Funding  
Submitted May 1, 2009**

*Testimony submitted by:*  
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The Association of American Cancer Institutes (AACI), representing 95 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration as the Labor, Health and Human Services Appropriations Subcommittee plans the fiscal year (FY) 2010 appropriations for the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

AACI applauds recent budgetary commitments—notably, increased funding for NIH and support from the Obama Administration through the American Recovery and Reinvestment Act of 2009—that have created a more encouraging landscape for cancer research compared to the last five years. We hope that this support will continue in the years ahead, to ensure that this recognition of the importance of biomedical research is sustained.

For FY 2010, AACI joins its colleagues in the biomedical research community in supporting the request in the President's budget proposal for \$6 billion in funding for cancer research in FY 2010, and his commitment to double funding for cancer research over the next five years.

AACI also requests that total funding to NIH be increased by 10 percent. The nation's investment in the NIH and National Cancer Institute (NCI) helps lead to scientific advances that can save lives and improve the health of Americans. Early funding increases helped speed the pace of cancer research, and this investment can be leveraged significantly with a renewed commitment to strong, sustained federal funding of medical research and, in particular, cancer research. AACI will work to ensure that Congress approves the maximum possible appropriations for NIH and NCI.

### **The Growing Cancer Burden**

In 2008, there were approximately 1.44 million new cases of cancer in the United States and approximately 565,650 deaths due to the disease.<sup>1</sup> About 150,090 new cancer cases were expected to be diagnosed among African Americans in 2009, with about 63,360 expected to die from the disease. In men, the death rate for all cancers combined continued to be substantially higher among African Americans than whites during 1975-2005. Similar trends were seen among women, although the gap is much smaller.<sup>2</sup>

Looking further into the future, the need for cancer care will expand dramatically. From 2010 to 2030, the total projected cancer incidence will increase by approximately 45%, from 1.6 million in 2010 to 2.3 million in 2030. This increase is driven by cancer diagnosed in older adults and minorities. A 67% increase in cancer incidence is anticipated for older adults, compared with an 11% increase for younger adults. A 99% increase is anticipated for minorities, compared with a 31% increase for whites. From 2010 to 2030, the percentage of all cancers diagnosed in older adults will increase from 61% to 70%, and the percentage of all cancers diagnosed in minorities will increase from 21% to 28%.<sup>3</sup>

The human toll of cancer is staggering, as is its financial toll; the NCI reports that in 2006, \$206.3 billion was spent on healthcare costs for cancer alone. Additionally, NCI acknowledges that the burdens of cancer—physical, emotional, and financial—are “unfairly shouldered by the poor, the elderly, and minority populations.”<sup>2</sup> The number of cancer diagnoses will only continue to climb as our population ages, with an estimated 18.2 million cancer survivors (those undergoing treatment, as well as those who have completed treatment) alive in 2020.<sup>3</sup>

### **Cancer Research: Benefiting all Americans**

Cancer research, conducted in academic laboratories across the country saves money by reducing healthcare costs associated with the disease, enhances the United States' global competitiveness, and has a positive economic impact on localities that house a major research center. While these aspects of cancer research are important, what cannot be overstated is the impact cancer research has had on individuals' lives—lives that have been lengthened and even saved by virtue of discoveries made in cancer research laboratories at cancer centers across the United States.

Though over a half-million Americans will die this year from the many diseases defined as cancer, progress is being made. Because of continued progress made by the nation's researchers, cancer death rates have continued to decline; between 1991 and 2004, the death rates for cancer

<sup>1</sup> *Cancer Facts and Figures 2008*. American Cancer Society; 2008. (The publication of Cancer Facts & Figures 2009 has been delayed due to the late release of the US final mortality data by the National Center for Health Statistics.)

<sup>2</sup> American Cancer Society. *Cancer Facts & Figures for African Americans 2009-2010*. Atlanta: American Cancer Society, 2009.

<sup>3</sup> Smith et al., “Future of Cancer Incidence in the United States: Burdens Upon an Aging, Changing Nation”, *J Clin Oncol* 2009; 27

<sup>4</sup> Cancer Statistics, 2008. CA: *Cancer Journal for Clinicians* 2008; 58(2): 71–96.

in men and women declined 18.4 percent and 10.5 percent, respectively.<sup>4</sup> Similarly, death rates among African Americans for all cancers combined have been decreasing since 1991 after increasing from 1975 to 1991. The decline was larger in men (2.5% per year since 1995) than in women (1.3% per year since 1997). Similar trends were observed among whites from 1991-2005, with a greater reduction in the rate among men than women.

Biomedical research has provided Americans with better cancer treatments, as well as enhanced cancer screening and prevention efforts. Some of the most exciting breakthroughs in current cancer research are those in the field of personalized medicine. In personalized medicine for cancer, not only is the disease itself considered when determining treatments, but so is the individual's unique genetic code. This combination allows physicians to better identify those at risk for cancer, detect the disease, and treat the cancer in a targeted fashion that minimizes side effects and refines treatment in a way to provide the maximum benefit to the patient.

In the laboratory setting, multi-disciplinary teams of scientists are working together to understand the significance of the human genome in cancer. For instance, the Cancer Genetic Markers of Susceptibility initiative is comparing the DNA of men and women with breast or prostate cancer with that of men and women without the diseases to better understand the diseases. The Cancer Genome Atlas is in development as a comprehensive catalog of genetic changes that occur in cancer. Another initiative, the Childhood Cancer Therapeutically Applicable Research to Generate Effective Treatments Initiative, is identifying targets that can lead to better treatments for young people with cancer.

These projects—along with the work being performed by dedicated physicians and researchers at cancer centers across the United States every day—have the potential to radically change the way cancer, as a collection of diseases, affects the people who live with it every day. Every discovery contributes to a future without cancer as we know it today.

#### **The Nation's Cancer Centers**

The nexus of cancer research in the United States is the nation's network of cancer centers that are represented by AACI. These cancer centers conduct the highest-quality cancer research anywhere in the world and provide exceptional patient care. The nation's research institutions, which house AACI's member cancer centers, receive an estimated \$3.17 billion<sup>5</sup> from NCI to conduct cancer research; this represents 66 percent of NCI's total budget. In fact, 85 percent of NCI's budget supports research at nearly 650 universities, hospitals, cancer centers, and other institutions in all 50 states. Because these centers are networked nationally, opportunities for collaborations are many—assuring wise and non-duplicative investment of scarce federal dollars.

In addition to conducting basic, clinical, and population research, the cancer centers are largely responsible for training the cancer workforce that will practice in the United States in the years to

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<sup>5</sup> *National Cancer Institute 2007 Fact Book*. U.S. Department of Health and Human Services, U.S. National Institutes of Health, 2007.

<sup>6</sup> *In Your Own Backyard: How NIH Funding Helps Your State's Economy*, Families USA, June 2008

come. Much of this training is dependent on federal dollars, via training grants and other funding from NCI. Sustained federal support will significantly enhance the centers' ability to continue to train the next generation of cancer specialists—both researchers and providers of cancer care.

By providing access to a wide array of expertise and programs specializing in prevention, diagnosis, and treatment of cancer, cancer centers play an important role in reducing the burden of cancer in their communities. The majority of the clinical trials of new interventions for cancer are carried out at the nation's network of cancer centers.

Beyond their health care and research roles, cancer centers are also reliable engines of economic activity for the nation as a whole, and for the communities and regions that they serve. For every dollar spent on biomedical research, a national average of \$2.21 in economic benefit results.<sup>6</sup>

#### **Ensuring the Future of Cancer Care and Research**

Because of an aging population, an increasing number of cancer survivors require ongoing monitoring and care from oncologists, and new therapies that tend to be complex and often extend life.

Demand for oncology services is projected to increase 48 percent by 2020. However, the supply of oncologists expected to increase by only 20 percent and 54 percent of currently practicing oncologists will be of retirement age within that timeframe. Also, alarmingly, there has been essentially no growth over the past decade in the number of medical residents electing to train on a path toward oncology as a specialty.<sup>7</sup>

Cancer physicians—while essential—are only one part of the oncology workforce that is in danger of being stretched to the breaking point. The Health Resources and Services Administration predicted that by 2020, over 1 million nursing positions will go unfilled, and a 2002 survey by the Southern Regional Board of Education projected a 12 percent shortage of nurse educators by last year.<sup>8</sup>

Without immediate action, these predicted shortages will prove disastrous for the state of cancer care in the United States. The discrepancy between supply and demand for oncologists will amount to a shortage of 9.4 to 15.1 million visits, or a shortage of 2,550 to 4,080 oncologists. The Department of Health and Human Services projects that today's 10-percent vacancy rate in registered nursing positions will grow to 36 percent, representing more than 1 million unfilled jobs by 2020.<sup>10</sup>

Greater federal support for training oncology physicians, nurses, and other professionals who treat cancer must be enacted to prevent a disaster within our healthcare system when demand for oncology services far outstrips the system's ability to provide adequate care for all.

<sup>7</sup> *Forecasting the Supply of and Demand for Oncologists: A Report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies*. American Society of Clinical Oncology, 2007.

<sup>8</sup> ONS: Ready to Collaborate with Other Policymakers to Ensure Future of Quality Cancer Care, *Oncology Times*, August 25, 2007; (29): 8-9.

#### **Americans Support Federal Funding for Research**

The research community has long understood the obstacles that are facing cancer research. Though the nuances of R01 grants and oncology workforce training may not be well understood by the average American, the people of the United States believe in supporting the disparate activities that make up America's biomedical research infrastructure.

In a 2007 Research!America poll, 91 percent of those surveyed believed it was somewhat or very important for policymakers to create more incentives to encourage individuals to pursue careers as nurses, while 89 percent believed the same for encouraging careers as physicians. Forty-seven percent of those surveyed agreed that the U.S. must increase investment in NIH to ensure our future health and economic security, and 54 percent favored annual 6.7 percent increases in funding for NIH in 2008, 2009, and 2010. An overwhelming majority—70 percent—agreed that the U.S. is losing its global competitive edge in science, technology, and innovation.

We encourage our Members of Congress to respond to the concerns of the American people by enhancing support for biomedical research that will lead to improved health for everyone in the United States and around the world.

#### **Conclusion**

These are exciting times in science and, particularly, in cancer research. The AACI cancer center network is unrivaled in its pursuit of excellence, and place the highest priority on affording all Americans access to that care, including novel treatments and clinical trials. It is through the power of collaborative innovation that we will accelerate progress toward a future without cancer, and research funding through the NIH and NCI is essential to achieving our goals.

Testimony of the Association of Public Television Stations (APTS), Larry Sidman, President & CEO and the Public Broadcasting Service (PBS), Paula Kerger, President & CEO  
 Tel: 202.654.4212, Email: [lsidman@apts.org](mailto:lsidman@apts.org)

**Testimony of the Association of Public Television Stations (APTS) and  
 the Public Broadcasting Service (PBS)  
 Before the House Committee on Appropriations, Subcommittee on Labor, Health and  
 Human Services, Education and Related Agencies**

On behalf of America's 361 public television stations, we appreciate the opportunity to submit testimony for the record on the current status of public television stations across America and their related needs. The fate of public television stations, and, with them, the informed communities they promote, lies in the hands of Congress and the Administration. Our goal is to work with your Committee to ensure that stations receive both the emergency appropriation necessary to stay on the air at a time when stations are most needed and the regular appropriations they need to expand their services in the digital age.

**Emergency Funding**

***FY 2010 Request: \$307 million***

In light of the financial crisis which has gripped the country, increased federal support for public broadcasting is perhaps more important now than ever before in the history of the industry. Stations are facing unprecedented revenue declines. Every revenue source upon which our operations depend is under siege. State funding support is in a wholesale free-fall. Financial contributions from foundations and underwriters, at the local and national levels, have declined precipitously. Individual contributions, the bed-rock of every public station's annual operating budget, are dropping, reflecting the effects of rising unemployment and declining personal discretionary income. In fact, a recent survey of our system's television stations indicated a marked decline in fundraising during the March 2009 pledge drive—by almost one-third—when compared to last year's fundraising.

As a result, we are beginning to witness the corresponding effects of these revenue shortfalls at the station level. In a survey of public television stations conducted last month, we found that 60 percent of public television stations have been forced to terminate employees, 29 percent have reduced salaries or benefits and 66 percent reported cuts in programming and services. These effects are not limited to the smaller stations. For example, WETA in Washington, DC, upon which the public television system relies for such outstanding programs as *The News Hour* and Ken Burns' epic *The War*, just announced a 13 percent reduction in workforce. KETC in St. Louis, creator of the award-winning television program and help-line initiative, *Facing the Mortgage Crisis*, announced in February that it is cutting staff by more than 10 percent. And Sesame Workshop, creator of public television's longest running and most identifiable children's program, *Sesame Street*, recently was forced to cut 20 percent of its staff.

This situation is compounded by the costs and disruptions associated with the delay in the transition from analog to digital broadcasting, which will cost the system approximately \$22 million.

The expected continued decline of the economy through 2009 foretells shortfalls of equal or greater severity than those currently facing local stations. Some local stations may disappear entirely, undermining public television's universal service mission. At a time when more people than ever are turning to public television and radio as a trusted source for news and information, our forty-year public-private partnership is in peril.

To address this dire financial shortfall, APTS and PBS respectfully request a one-time appropriation of \$307 million in the FY 2010 appropriations process. Based on recent in-depth surveys of radio and television stations, and our own actual experience over the past several years, this request reflects our most accurate projections of the amount of funding that will be essential to fulfill critical operating requirements for FY 2010.

We greatly appreciate Congress' recognition of the importance of two-year advance funding for the Corporation for Public Broadcasting (CPB). However, additional funding for CPB in FY 2012 would simply be too late to stem the tide of losses at public broadcasting stations. Therefore, we believe that a one-time, additional appropriation to CPB for FY 2010 is indispensable to forestall further declines in programming and services at the station level.

#### **Annual Appropriations Requests**

Our remaining requests are a testament to the high-quality, effective services our local stations offer—impacting their communities on-air, on-line and on-the-ground. More than 40 years after the inception of public television, local stations continue to serve as the treasured cultural institutions envisioned by their founders, reaching America's local communities with unsurpassed programming and services. Furthermore, the power of digital technology has enabled stations to greatly expand their delivery platforms to reach Americans where they are increasingly consuming media—online and on-demand—in addition to on-air.

Public television considers education to be one of its core missions. Since its inception, stations have worked to improve student achievement in schools and communities nationwide. In fact, 76 percent of stations partner with K-12 schools and districts, 85 percent of stations align their content to local, state or national standards, and 74 percent of stations create Science Technology Engineering and Math (STEM)-related content. Through its two authorized programs, Ready To Learn and Ready To Teach, public television continues to provide teachers and students with the high quality resources they need to succeed in the 21<sup>st</sup> century economy.

#### ***Corporation for Public Broadcasting—FY 2012 Request: \$542 million, advance funded***

Funds appropriated to CPB reach local stations in the form of Community Service Grants (CSGs). CSGs, while accounting for approximately 15-20 percent of the average station's overall budget, serve as the backbone of support for stations. Stations are also able to leverage those CSGs to raise additional funds from state legislatures, private foundations and their viewers.

Funding through CPB is absolutely essential to public television stations. A 2007 GAO report concluded that federal funding, such as CSGs, is an irreplaceable source of revenue, and that "substantial growth of nonfederal funding appears unlikely." It also found that "cuts in federal funding could lead to a reduction in staff, local programming or services."

Federal support for CPB and local public television stations has resulted in a nationwide system of locally owned and controlled, trusted, community-driven and community responsive media entities. For the sixth consecutive year, a 2009 Roper poll rated public television the most trusted institution among nationally known organizations. And in a recent report, the American Academy of Pediatrics recommended that Congress increase funding for public television, characterizing it as “the sole source for high quality, educational, noncommercial programming for children.”

In addition, the advent of digital technology has created enormous potential for stations, allowing them to bring content to Americans in new, innovative ways while retaining our public service mission. Public television stations are now utilizing a wide array of digital tools to expand their current roles as educators, local conveners and vital sources of trusted information at a time when their communities need them most.

For example, in St. Louis, a mortgage crisis initiative conceived of and led by local station KETC has brought dozens of independent community organizations together to help families save their homes from foreclosure. With a strong broadcasting and web infrastructure in place, the station links families in need with a network of community assistance organizations, and also provides content about managing debt and financial literacy. Since this initiative began in July 2008, 8,200 families have been helped.

This commitment to localism, one of public television’s core missions, is replicated nationwide. Stations’ deep ties to their communities have allowed them to tailor solutions to address pressing national priorities in ways that best fit local needs. For example, upon witnessing firsthand the harsh effects of the nation’s healthcare crisis in their local communities, several stations have begun to tackle the problem head-on. For example, KQED in San Francisco, CA, recently produced the program *Working Uninsured*, which took a look at the plight of working Americans who, for various reasons, struggle with the extraordinary challenge of life without health insurance. And Twin Cities Public Television launched the Community Health Awareness Initiative to raise awareness of critical health care issues and provide practical health information. Examples of the programming produced include: *Breast Cancer: Your Health in Your Hands* (English, Spanish, Hmong, and Somali versions), *The New Medicine in Minnesota*, *A Lion in the House: Minnesotans Connect* (a program on children’s cancer), *Decoding Part D: Medicare’s Drug Benefit*, *Medicare Rx: Enrollment Countdown*, and *Remaking Minnesota Medicine*. Myriad more efforts, many addressing education, civic engagement and other issues, are underway nationwide.

In order for our stations to continue playing this vital role in their communities, APTS and PBS respectfully request \$542 million for CPB, advance funded for FY 2012. Advance funding is essential to the mission of public broadcasting. The longstanding practice ensures that stations are able to insulate programming decisions from political influence, leverage the promise of federal dollars to raise state, local and private funds, and have the critical lead-in time needed to plan and produce programs.



**Digital Funding—FY 2010 Request: \$40 million**

Public television stations have been at the forefront of the digital transition, embracing the technology early and recognizing its benefits to their viewers. Fortunately, Congress wisely recognized that the federally mandated transition to digital broadcast would place a hardship on public television's limited resources. Since 2001, Congress has provided public television stations with funds to ensure that they have the ability to continue to meet their public service mission and deliver the highest quality educational, cultural and public affairs programming post-transition.

Although this year will mark the end of analog broadcast, a complete transition that allows public television stations to fully replicate in digital their current analog services, including the creation of local programming, will continue for a time to come. As stations have completed the transition of their main transmitters, they will continue to convert their master controls, cameras, digital storage equipment and other necessary studio equipment well beyond 2009—equipment necessary to maintain their ability to produce and distribute educational and enriching local programming.

Unlike most commercial broadcasters, public television has used this new public digital spectrum to maximize programming choices by offering an array of new channel options, including the national offerings of *V-me* (the first 24-hour, Spanish-language, educational channel), *World*, and *Create*.

More importantly, stations have also used these multicast capabilities to expand their local offerings with digital channels dedicated to community or state-focused programming. Some stations have even utilized this technology to provide gavel-to-gavel coverage of their state legislatures. In addition, digital broadcasting has enabled stations to double the amount of noncommercial, children's educational programming offered to the American public.

APTS and PBS respectfully request \$40 million in CPB Digital funding for FY2010 to enable stations to fully leverage this groundbreaking technology.

**Ready To Learn—FY 2010 Request: \$32 million**

Ready To Learn is improving the reading skills of all of America's children through fully researched, engaging educational television and on-line content, with a particular focus on over 150,000 low income households in 23 states and the District of Columbia. Ready To Learn content, based on the findings of the National Reading Panel of 2000, is on-air—reaching 99 percent of the country's television households through Public Television stations—as well as on-line, and on the ground in classrooms and communities.

In addition to successful on the ground partnerships with local stations, national nonprofit organizations and state education leaders, including the Council of Chief State School Officers, Ready To Learn's signature component is its research-based and teacher-tested television programs that teach key reading skills, including: *SUPER WHY!*, *WordWorld*, *Martha Speaks*, *Sesame Street*, *Between The Lions*, and *The Electric Company* produced by the best educational children's content producers.

Recent evaluations of one such program, *SUPER WHY!*, tell a story of enormous success.

The evaluation found that preschool children who watched the program performed significantly better on most of the standardized measures of early reading achievement when compared with those preschool children who watched an alternate program. In fact, pre-test to post-test gains averaged 28.7 percent for SUPER WHY! viewers compared with an average gain of 13.2 percent for alternate program viewers. Specifically, preschool children demonstrated significant growth in targeted early literacy skills featured in SUPER WHY!, including alphabet knowledge, phonological and phonemic awareness, symbolic and linguistic awareness, and comprehension.

In addition, SUPER WHY!'s 2008 five-day Summer Reading Camps—33 camps in 19 communities with 454 low-income Pre-K children—produced measurable results in raising children's reading skills through their interaction with strategically executed instructional materials designed to boost letter knowledge, decoding, encoding and reading ability. During these camps, preschoolers showed an 84 percent gain in phonics skills and a 139 percent gain in word recognition skills.

With additional funding, Ready To Learn can continue to meet the needs of those most lacking reading skills by extending the program's community engagement and partnership-driven work to additional high-need communities nationwide and by increasing capacity and reach through the innovative use of digital media.

APTS and PBS respectfully request \$32 million for Ready To Learn in FY2010.

***Ready To Teach—FY 2010 Request: \$17 million***

Ready To Teach was first introduced in Congress in 1994 as a demonstration project to show how distance learning technology coupled with public broadcasting's rich educational content could help teachers enhance their proficiency in specific curriculum areas.

Later authorized under the *No Child Left Behind* Act, Ready To Teach currently funds the development of digital educational services aimed at enhancing teacher performance. Through four Ready To Teach services—*PBS TeacherLine*, *e-Learning for Educators*, *VITAL* and *HELP*—PBS, Alabama Public Television, Thirteen/WNET and Rocky Mountain PBS (RMPBS), have provided online professional development targeted toward PreK-12 educators, video clips aligned to math and reading state standards, and an English-Language Learner program for math instruction.

Together, Ready To Teach programs have served nearly 100,000 educators since 2001, and represent an enormously successful utilization of innovative, digital technology for the benefit of teachers and their students in the 21<sup>st</sup> century classroom.

APTS and PBS respectfully request \$17 million in FY 2010 in order to build the library of professional development courses, resources and support materials for teachers through the public broadcasting infrastructure, and increase the number of local stations able to participate in Ready To Teach, thereby increasing the efforts to prepare highly qualified teachers.

**Association of Rehabilitation Nurses  
Written Testimony to the LHHS Appropriations Subcommittee  
ARN President, Donna Jernigan, BSN, RN, MS, CRRN, NE-BC  
(919) 498-2214 and [dpjernigan@windstream.net](mailto:dpjernigan@windstream.net)  
May 1, 2009**

Introduction

On behalf of the Association of Rehabilitation Nurses (ARN), I appreciate having the opportunity to submit written testimony to the House LHHS Subcommittee regarding funding for nursing and rehabilitation related programs in fiscal year (FY) 2010. ARN represents professional nurses who work to enhance the quality of life for those affected by physical disability and/or chronic illness. ARN understands that Congress has many concerns and limited resources, but believes that chronic illness and physical disability are heavy burdens on our society that must be addressed.

Rehabilitation Nurses and Rehabilitation Nursing

Rehabilitation nurses help individuals affected by chronic illness and/or physical disability adapt to their disability, achieve their greatest potential, and work toward productive, independent lives. They take a holistic approach to meeting patients' medical, vocational, educational, environmental, and spiritual needs. Rehabilitation nurses begin to work with individuals and their families soon after the onset of a disabling injury or chronic illness. They continue to provide support in the form of patient and family education and empower these individuals when they return home, or to work, or school. The rehabilitation nurse often teaches patients and their caregivers how to access systems and resources.

Rehabilitation nursing is a philosophy of care, not a work setting or a phase of treatment. Rehabilitation nurses base their practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) collaborating with other specialists; (3) providing ongoing patient/caregiver education; (4) setting goals for maximal independence; and (5) establishing plans of care to maintain optimal wellness. Rehabilitation nurses practice in all settings, including freestanding rehabilitation facilities, hospitals, long-term subacute care facilities/skilled nursing facilities, long-term acute care facilities, comprehensive outpatient rehabilitation facilities; and private practice, just to name a few.

To ensure that patients receive the best quality care possible, ARN supports federal programs and research institutions that address the national nursing shortage and conduct research on medical rehabilitation and nursing and traumatic brain injury. Therefore, ARN respectfully requests that the Subcommittee provide increased funding for the following programs:

*Association of Rehabilitation Nurses  
FY 2010 Written Testimony Submitted to the  
House LHHS Appropriations Subcommittee  
May 1, 2009*

Nursing Workforce and Development Programs at the Health Resources and Services  
Administration (HRSA)

ARN supports efforts to resolve the national nursing shortage, including appropriate funding to address the shortage of qualified nursing faculty. Rehabilitation nursing requires a high-level of education and technical expertise, and ARN is committed to assuring and protecting access to professional nursing care delivered by highly-educated, well-trained, and experienced registered nurses for individuals affected by chronic illness and/or physical disability.

According to the Department of Health and Human Services, the federal Nursing Workforce Development program at the Health Resources and Services Administration (HRSA), an estimated 36,750 nurses need to be recruited, educated, and retained to meet the current demands of the health care system. Efforts to recruit and educate individuals interested in nursing have been thwarted by the shortage of nursing faculty. In 2007, due to the nursing faculty shortage, more than 40,000 qualified applicants were not able to matriculate in nursing school. The number of full-time nursing faculty required to "fill the nursing gap" is approximately 40,000, and, currently, there are less than 20,000 full-time nursing faculty members. Further exacerbating this issue, HRSA predicts that the nursing shortage is expected to grow to 41 percent by 2020.

**ARN strongly supports the national nursing community's request of \$215 million in FY 2010 funding for federal Nursing Workforce Development programs at HRSA.**

National Institute on Disability and Rehabilitation Research (NIDRR)

The National Institute on Disability and Rehabilitation Research (NIDRR) provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. As one of the components of the Office of Special Education and Rehabilitative Services at the U.S. Department of Education, NIDRR operates along with the Rehabilitation Services Administration and the Office of Special Education Programs.

The mission of NIDRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDRR conducts comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities. NIDRR's focus includes research in areas such as employment; health and function; technology for access and function; independent living and community integration; and other associated disability research areas.

**ARN strongly supports the work of NIDRR and encourages Congress to provide the maximum possible FY 2010 funding level.**

*Association of Rehabilitation Nurses  
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May 1, 2009*

National Institute of Nursing Research (NINR)

ARN understands that research is essential for the advancement of nursing science, and believes new concepts must be developed and tested to sustain the continued growth and maturation of the rehabilitation nursing specialty. The National Institute of Nursing Research (NINR) works to create cost-effective and high-quality health care by testing new nursing science concepts and investigating how to best integrate them into daily practice. NINR has a broad mandate that includes seeking to prevent and delay disease and to ease the symptoms associated with both chronic and acute illnesses. NINR's recent areas of research focus include the following:

- End of life and palliative care in rural areas;
- Research in multi-cultural societies;
- Bio-behavioral methods to improve outcomes research; and
- Increasing health promotion through comprehensive studies.

**ARN respectfully requests \$178 million in FY 2010 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.**

Traumatic Brain Injury (TBI)

Approximately 1.5 million American children and adults are living with long-term, severe disability, as a result of traumatic brain injury (TBI). Moreover, this figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Iraq and Afghanistan.

The annual national cost of providing treatment and services for these patients is estimated to be nearly \$60 million in direct care and lost workplace productivity. Continued fiscal support of the Traumatic Brain Injury Act will provide critical funding needed to further develop research and improve the lives of individuals who suffer from traumatic brain injury.

Continued funding of the TBI Act will promote sound public health policy in brain injury prevention, research, education, treatment, and community-based services, while informing the public of the need support for individuals living with TBI and their families.

ARN strongly supports the current work being done by the Centers for Disease Control and Prevention (CDC) and HRSA on TBI programs. These programs contribute to the overall body of knowledge in rehabilitation medicine.

**ARN urges Congress to support the following FY 2010 funding requests for programs within the TBI Act: \$10 million for CDC's TBI registries and surveillance, prevention and national public education and awareness efforts; \$20 million for the HRSA Federal TBI State Grant Program; and \$13.3 million for the HRSA Federal TBI Protection and Advocacy Systems Grant Program.**

*Association of Rehabilitation Nurses  
FY 2010 Written Testimony Submitted to the  
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May 1, 2009*

Conclusion

ARN appreciates the opportunity to share our priorities for FY 2010 funding levels for nursing and rehabilitation programs. ARN maintains a strong commitment to working with Members of Congress, other nursing and rehabilitation organizations, and other stakeholders to ensure that the rehabilitation nurses of today continue to practice tomorrow. By providing the FY 2010 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for patients requiring rehabilitation from chronic illness and/or physical disability.

**Testimony Submitted on behalf of the  
Association of University Programs in Occupational Health and Safety (AUPOHS)**

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President, Association of University Programs in Occupational Health and Safety

**May 1, 2009**

Thank you for the opportunity to submit testimony to the Subcommittee in support of funding for the National Institute for Occupational Safety and Health (NIOSH) and for the NIOSH-funded Education and Research Centers (ERCs). My name is Dr. Sarah Felknor. I am the director of the Southwest Center for Occupational and Environmental Health located at the University of Texas Health Science Center at Houston.

**I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS)**, an organization that represents 17 multi-disciplinary, university-based Education and Research Centers (ERCs) which are funded by NIOSH, the federal agency responsible for providing education and training for the prevention of work-related injuries and illnesses. The ERCs are regional resources for all parties involved with occupational health and safety – industry, labor, government, academia, and the general public. Collectively, the ERCs provide training and research resources to every Public Health Region in the United States. ERCs play the following roles in helping the nation reduce losses associated with work-related illnesses and injuries:

- Prevention Research: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.
- Professional Training: Graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.
- Research Training: Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.
- Continuing Education: Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 17 ERCs as well as through distance learning technologies.
- Regional Outreach: Responding to specific requests from local employers and workers on issues related to occupational health and safety.

***The Scope of the Problem of Occupational Injury and Illnesses***

The many causes of occupational injury and illness represent a striking burden on America's health and well-being. Yet, despite significant improvements in workplace safety and health over the last several decades:

- Each day, an average of 9,000 U.S. workers sustain disabling injuries on the job, 16 workers die from an injury suffered at work, and 137 workers die from work-related diseases.
- In 2005, more than 4.2 million workers sustained work-related injuries and illnesses in the private sector alone.
- The Liberty Mutual 2005 Workplace Safety Index estimates that employers spent \$50.8 billion in 2003 on wage payments and medical care for workers hurt on the job; the indirect costs exceeded \$200 billion.

This is an especially tragic situation because **most work-related fatalities, injuries and illnesses are preventable** with effective, professionally directed, health and safety programs.

Here are some of the important issues that NIOSH deals with:

- When the Senate office buildings were attacked with anthrax, NIOSH and ERC professionals responded.
- NIOSH, helped by ERCs, took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia.
- We are now seeing serious health problems in the workers who were at Ground Zero. NIOSH and the New York - New Jersey ERC are playing the major lead in their medical follow-up.
- NIOSH is the leading federal agency conducting research and providing guidance on the worker health implications in the emerging field of nanotechnology.

We need manpower to address the sorts of issues mentioned above and it is the NIOSH ERCs that produce the graduates who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide training that is multi-disciplinary, ERC graduates protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training such qualified professionals, the country continues to have ongoing shortages.

Furthermore, we do not live in a static environment. The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers. The rapid development of nanotechnology poses a number of unanswered questions with regard to workplace risk factors that the science or workplace safety and health will have to answer.



In addition to factors that increasingly affect the vulnerability of our workers, we constantly face new threats to worker health. As an example, one of the greatest concerns regarding a potential outbreak of avian influenza is the drastic effect it may have on our workforce. The protection of health care workers in particular will become a major priority if we are to protect our population.

Despite being the primary federal agency for occupational disease and injury prevention in the nation, NIOSH receives only about one dollar per worker per year for its mission of research, professional education, and outreach.

#### ***Homeland Security***

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing occupational safety and health professionals to identify and ameliorate vulnerabilities to terrorist attacks and other workplace hazards and increase readiness to respond to biological, chemical, or radiological attacks.

Thanks to the Subcommittee's support for occupational health and safety research, NIOSH developed more effective methods to test for anthrax contamination in congressional offices. These procedures were quickly adopted by the Coast Guard, the FBI, and government building contractors. More recently, in response to ongoing safety concerns regarding the tunnels under the U.S. Capitol Complex, NIOSH was asked to evaluate health hazards in the tunnels for workers who maintain the plumbing that provides steam and chilled water to Congress, the Library of Congress, the Supreme Court and other federal buildings.

In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize losses in the event of a disaster. NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and conducting ongoing activities to safeguard the health of clean-up workers. Additionally, NIOSH is now administering grants to provide health screening of World Trade Center responders. Included in the grantees is the New York - New Jersey ERC.

In the face of the growing concerns surrounding homeland security, ERCs have rapidly upgraded research coordination and expanded training opportunities, including sponsoring national and regional forums on response to bioterrorism and other disasters.

#### ***The Need for Occupational Safety and Health Manpower***

The NIOSH ERCs were reviewed by the DHHS Office of the Inspector General in 1995. The resulting report affirmed the efficacy of the ERCs in producing graduates who pursue careers in occupational safety and health. Since the ERCs are regional, they are ready to respond to various trends in industries throughout the country. In the southeast, for example, automobile manufacturing has been the major growth industry since 2000. Alabama now has major facilities for Mercedes, Honda and Hyundai that employ thousands of workers. Graduates from the Deep South Education and Research Center fill key positions in the safety, health and environmental

programs at all of these facilities. And because they provide training that is multi-disciplinary, ERCs graduate professionals can protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training qualified occupational health and safety professionals, the country continues to have ongoing shortages. The manpower needs are especially acute for doctoral-level trained professionals who can conduct research and help in implementing the National Occupational Research Agenda (NORA).

In May 2000, the Institute of Medicine issued its final report on the education and training needs for occupational safety and health professionals in the United States. This report concluded that “the continuing burden of largely preventable occupational diseases and injuries and the lack of adequate occupational safety and health services in most small and many larger workplaces indicate a clear need for more occupational safety and health professionals at all levels.” Specific needs identified by the IOM report include:

- An insufficient number of doctoral-level graduates in occupational safety, thus limiting the nation’s capacity to perform essential research and training in traumatic injury prevention.
- An inability to attract physicians and nurses into formal occupational safety and health academic training programs, thus limiting the resources needed to deliver occupational health services.

ERCs are accomplishing the critical mission of filling these gaps by preparing expert researchers and practitioners in occupational safety and health.

***Recommendation for Fiscal Year 2010***

In fiscal year 2010 AUPHHS requests \$340.1 million, a \$50 million increase for NIOSH over the fiscal year 2009 appropriated level, and within that increase, not less than a \$10 million increase for Education and Research Centers (ERCs).

A \$50 million increase would enable NIOSH to keep pace with the changing nature of work and ensure that research and education to prevent work-related disease and injuries remain a high priority. Given that much of NIOSH’s extramural research program is carried out by the Education and Research Centers (ERCs), sustaining the academic infrastructure provided by the ERCs is essential. Our recommendation would ensure that our nation’s universities have the capacity and manpower to implement these initiatives and expand training programs to improve the health and productivity of American workers.

The ERCs play an essential role in preventive health research and the training of occupational safety and health professionals, many of which are in short supply. The 17 ERCs are distributed throughout the U.S. and have a critical community outreach function, as well as serve as local resources of occupational safety and health expertise. A \$10 million increase will bring the total budget for the 17 ERCs to \$33.5 million and promote achievement of the NIOSH strategic goal to increase the technical proficiency of the occupational safety and health professionals who lead occupational safety and health practice in both the private and public sectors.

Thank you for the opportunity to report the great need for research and training in occupational safety and health.

**NIOSH-supported Education and Research Centers (ERCs)**

- Alabama Education and Research Center (*UA at Birmingham, Auburn University, and University of Alabama*)
- Northern California Education and Research Center (*UC Berkeley, UC Davis, UCSF*)
- Southern California Education and Research Center (*UCLA and UC Irvine*)
- Cincinnati Education and Research Center (*University of Cincinnati*)
- Mountain and Plains Education and Research Center (*University of Colorado Denver (CU), Colorado State University (CSU), National Jewish Medical and Research Center (NJMRC), Denver Health and Hospital Authority (DHHA) and the University of New Mexico Health Sciences Center (UNM)*)
- Harvard Education and Research Center
- Illinois Education and Research Center (*University of Illinois at Chicago*)
- Heartland Center for Occupational Health and Safety (*University of Iowa*)
- Johns Hopkins Education and Research Center
- Michigan Education and Research Center (*University of Michigan*)
- Midwest Center for Occupational Health and Safety (*University of Minnesota*)
- New York /New Jersey Education and Research Center (*Mount Sinai School of Medicine, Hunter College School of Health Sciences, New Jersey Institute of Technology, New York University, University of Medicine and Dentistry of New Jersey*)
- North Carolina Occupational Safety and Health ERC (*UNC at Chapel Hill*)
- Sunshine ERC (*University of South Florida*)
- Southwest Center for Occupational and Environmental Health (*University of Texas*)
- Rocky Mountain Center for Occupational and Environmental Health (*University of Utah*)
- Northwest Center for Occupational Health and Safety (*University of Washington*)

**Fiscal Year 2010 Testimony**

**United States House of Representatives**

**Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education & Related Agencies**

**May 1, 2009**

*Contact: Kerri Wade, Associate Director of Government and Media Affairs for AWHONN at  
(202) 261-2427 or kwade@awhonn.org*

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) appreciates the opportunity to provide testimony on fiscal year 2010 appropriations for the Department of Health and Human Services (HHS).

AWHONN is a nonprofit membership organization made up of 23,000 nurses who care for mothers, their newborns and women of all ages. AWHONN members are registered nurses, nurse practitioners, certified nurse-midwives and clinical nurse specialists who work in hospitals, independent practices, universities and community clinics throughout the United States. Our mission is to promote the health of women and newborns.

Nurses are typically the first and most consistent point of contact in the health care setting. Evidence suggests that they spend more time with patients — up to four times on average — than any other health care provider. As such, nurses have a unique perspective on the health care system and the public health programs and agencies funded under HHS.

We thank the Subcommittee for providing generous funding in past years and we are truly appreciative for the public health funding included in the American Recovery and Reinvestment Act of 2009. Recognizing the challenges the Subcommittee will face in FY 2010 in reconciling various expenditures in the face of overall budget deficits, please find our funding recommendations for FY 2010 below.

**Health Resources and Services Administration (HRSA)**

As a member of the Friends of the Health Resources and Services Administration coalition, AWHONN recommends \$8.5 billion for HRSA in FY 2010.

HRSA programs support health professions education, health care services for underserved populations, programs to address the special needs of mothers and children, and more. For several years, HRSA has suffered from relatively level funding. In light of these difficult economic times, support for the nation's safety net system is especially critical.

One of the most important aspects of HRSA's mission is to ensure a health care workforce that is sufficient to meet the needs of patients and communities.

- *Nursing Workforce Development Programs, Title VIII of the Public Health Service Act*

Along with the Nursing Community coalition, AWHONN recommends \$215 million for Title VIII programs in FY 2010. An adequate supply of nurses is essential to ensuring that all Americans receive quality health care. Title VIII programs help to address the nation's ongoing nursing and nurse faculty shortage by providing scholarships and loan repayment programs to nursing students, recent graduates and nursing school faculty. Title VIII also provides grants to schools of nursing and health centers to foster greater diversity and improved retention rates in the nursing workforce.

- *Maternal and Child Health (MCH) Block Grant, Title V of the Social Security Act*

AWHONN recommends \$850 million for the MCH Block Grant in FY 2010. The MCH Block Grant, the only federal program of its kind, is devoted to improving the health of women and children. For over 70 years, the program has provided a source of flexible funding for states and territories to address their unique needs related to improving the health of mothers and children. Today, this program provides prenatal services to over two million mothers - almost half of all mothers who give birth annually - and primary and preventive care to over 17 million children, including almost one million children with special needs. Fully funding the MCH block grant will enable states to expand critical health services.

We recommend \$30 million for newborn screening activities, which are currently funded under the MCH block grant Special Projects of Regional and National Significance. Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal, and functional conditions in newborns. Screening detects disorders in newborns that, if left untreated, can cause disability, mental retardation, serious illnesses or even death. While nearly all babies born in the U.S. undergo newborn screening for genetic birth defects, the number and quality of these tests vary from state to state.

#### **National Institutes of Health (NIH)**

AWHONN, along with others in the science advocacy community, support increased funding for NIH in FY 2010. Scientific research done at the NIH is leading to better patient care. In fact, federally funded research is responsible for nearly every major medical advancement in the last 50 years. While AWHONN supports the NIH in its entirety, several Institutes are especially important to the advancement of nursing and the health of women and newborns.

- *The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)*

The rate of preterm birth has increased 20 percent since 1990. The NICHD supports critical research into the causes and treatments for preterm birth.

AWHONN, along with the March of Dimes, recommends that Congress provide at least a seven percent increase for NICHD in FY 2010, a portion to be used to begin establishing transdisciplinary research centers that focus on preterm birth. NICHD needs additional resources to expand research on the underlying causes of preterm birth taking into account the recommendations of the experts who participated in the Surgeon General's Conference on Preterm Birth in the summer of 2008.

- *National Institute of Nursing Research (NINR)*

AWHONN, along with the American Nurses Association and the American Association of Colleges of Nursing, recommends \$178 million for NINR in FY 2010.

NINR supports nurse-led research that contributes to advancing high quality, evidence based care across the lifespan. Research at NINR has targeted, among other topics, health disparities, risk reduction, chronic illnesses and care for rural and underserved populations. NINR promotes a uniquely important nursing perspective, as there is no caregiver that interacts with patients more or is more trusted by patients than nursing professionals. There is no other body that funds important nursing research similarly in this country, and NINR research has contributed measurably to more efficient and effective health care as our nation struggles to fill continuing staffing shortages and gaps in health care services.

#### **Centers for Disease Control and Prevention (CDC)**

The CDC is dedicated to protecting health and promoting quality of life through the prevention and control of disease, injury and disability. While AWHONN supports the CDC in its entirety, several agencies and programs are especially important to the advancing the health of women and newborns.

- *Safe Motherhood/Infant Health*

The Safe Motherhood/Infant Health program works to promote infant and reproductive health. AWHONN is especially concerned with issues associated with prematurity. Preterm birth is the leading cause of neonatal death in the U.S. In 2006, more than half a million babies – one in eight babies – were born prematurely in the U.S.

In 2005, AWHONN launched its Late Preterm Initiative to address the special needs of infants born between 34 and 36 completed weeks of gestation. While many late preterm infants may appear healthy at birth, they are at risk for prematurity-related complications, increased morbidity and mortality and have an increased rate of re-hospitalization in the first month of life.

Currently, the CDC is partnering with a number of universities and organizations to support research related to preterm birth and the reasons for disparities between racial and ethnic groups. AWHONN recommends a \$6 million increase in the preterm birth line FY 2010. This funding will allow the CDC to expand epidemiological work to evaluate

the social, biological and medical factors associated with preterm birth as authorized in the PREEMIE Act of 2006 (P.L. 109-450).

- *National Center on Health Statistics (NCHS)*

NCHS is the nation's principal health statistics agency, providing critical data on all aspects of the U.S. health care system. The agency provides data on health care trends, information that is essential for public health planning. However, current funding levels are threatening the collection of vital information, especially complete data on maternity and infant health status.

AWHONN, along with the Friends of NCHS, recommends at least \$137.5 million for NCHS in FY 2010. Additionally, we urge Congress to allocate \$15 million bolus funding to support states and territories as they implement the 2003 birth certificates and electronic systems to collect these data.

AWHONN thanks the Subcommittee for your consideration and greatly appreciates this opportunity to submit testimony. For further information, please contact: Kerri Wade, Associate Director of Government and Media Affairs for AWHONN at: (202) 261-2427 or [kwade@awhonn.org](mailto:kwade@awhonn.org).

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**STATEMENT OF  
SUSIE GORDEN  
DIRECTOR OF PUBLIC POLICY  
BIG BROTHERS BIG SISTERS OF AMERICA  
PHILADELPHIA, PA**

**SUBMITTED TO  
THE HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON THE DEPARTMENT OF LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**ON BEHALF OF BIG BROTHERS BIG SISTERS  
MAY 5, 2009**

Big Brothers Big Sisters supports \$17 million in Fiscal Year 2010 for the Department of Education's Mentoring programs, \$50 million for the Mentoring Children of Prisoners program and \$50 million for the Volunteer Generation Fund.



Mr. Chairman, I am pleased to have the opportunity to submit this testimony for the Subcommittee's record.

Big Brothers Big Sisters is the nation's oldest and largest mentoring organization. We have grown over the last 105 years to serve more than 250,000 at-risk youth in communities across the nation. Our 392 agencies are located in all 50 states, Guam and Puerto Rico. We match at-risk youth with a caring adult in a one-to-one mentoring relationship. These matches make a significant difference in the life of a child and are the foundation for developing the full potential of boys and girls as they grow to become competent, confident and caring men and women. Big Brothers Big Sisters offers an array of programs and services that focus on promoting positive youth development, helping each child discover his or her full potential.

With 17 million at-risk children growing up in America, the need for a proven strategy to reverse the statistics and to support their successful development has never been more critical. We believe that BBBS mentoring provides a significant return on investment, particularly compared to the consequences of social and educational failure. According to Independent Sector, the value of volunteer work was estimated at \$20.25 per hour in 2008. Last year, our Bigs contributed over 13 million volunteer hours at an estimated value of \$676 million.

Big Brothers Big Sisters' original, core program model is its community-based match. Bigs are matched with Littles referred to the program by a parent, and typically a match will spend about three hours per week together. Professional case-management staff at each local agency guide Bigs and provide them with the support necessary to ensure a healthy and lasting relationship with their Littles. It is through the relationship with these committed adults that at-risk children can begin to gain their own sense of self-confidence and develop healthy aspirations for the future.

Research has shown that BBBS mentoring works as a strategy to support at-risk youth. In 1995, Public/Private Ventures released its landmark impact study, which found that children matched with a Big Brother or Big Sister were:

- 46 percent less likely to begin using illegal drugs,
- 27 percent less likely to begin using alcohol,
- 52 percent less likely to skip school,
- 37 percent less likely to skip a class,
- more confident of their performance in schoolwork, and
- getting along better with their families.

#### **School-Based Mentoring (Mentoring for Success Grants)**

Our mentoring programs have grown exponentially over the last ten years. A major source of this growth is the expansion of Big Brothers Big Sisters' school-based program model. Locating our service in schools has offered a strong complement to the traditional community-based approach and has resulted in a significant increase in volunteer recruitment. Further, because children are referred by teachers, it connects the positive impact of the BBBS relationships directly with the educational enrichment for each matched child.

The President's Fiscal Year 2010 budget outline for the Department of Education has recommended that the Department's mentoring program be eliminated. This recommendation was made in follow-up to a federal study examining outcomes for school-based mentoring. The findings of the study are generating important and welcome dialogue. Big Brothers Big Sisters appreciates the focus on quality programs and has reached out to the Administration to offer our input in finding the most effective way to achieve positive outcomes for children.

We believe that well-run school based mentoring programs can and do have real impact. We have both the local and national evidence to prove this, including a more recent evaluation by P/PV. In fact, findings from the P/PV study led us to adopt significant changes to the way we run our own school-based programs in order to ensure longer and stronger matches that lead to concrete and measurable outcomes for the young people we serve. As a learning organization, we take seriously our responsibility to respond to research and continually improve our service delivery.

In 2003, with support from Atlantic Philanthropies, Big Brothers Big Sisters began a comprehensive study of our school-based mentoring program and evaluated impacts on randomly selected mentored youth compared to non-mentored youth in a control group. The scope of the study paralleled the BBBS Impact Study of Community-Based Mentoring conducted by P/PV in the 1990s and was the first nationwide, randomized study of school-based mentoring ever undertaken.

Among the findings:

- Three factors lead to better outcomes
  1. Socio-emotional match activities
  2. Matches that met more often and for longer periods
  3. A strong school environment and involvement by teachers and principals
- School-based mentoring has positive academic outcomes during the first year of the match, including higher grades, higher feelings of academic competence, greater number of assignments completed, fewer serious school infractions, and less skipping of school
- But largely because so many matches did not continue into the second year, these outcomes were for the most part not sustained in the second year.
- Training, supervision and school support are critical in fostering stronger and longer relationships
- The cost of school-based mentoring is only slightly less than community-based mentoring

The challenge was clear: longer matches and closer relationships meant stronger impacts and so how were we going to create longer matches and their corresponding increased, longer-lasting outcomes? The recommendations, coming out of the Study, of our internal School-Based Mentoring Task Force were:

- Start matches as early in the school year as possible
- Ensure that volunteers provide at least one school year of mentoring
- Build programs in feeder schools to sustain matches and provide youth with consistency through school transitions

- Select supportive schools for program involvement and continually foster these partnerships
- Explore ways to bridge the summer gap such as taking school-based mentoring out of the school year and increasing match contacts and treating school-based mentoring as a year-round program with strong match support
- Develop indices of match length that reflect the summer break and, in this way, are more sensitive predictors of impacts
- Explore more ways to provide volunteers (particularly young volunteers) with the support and ongoing training they need to create high-quality, effective mentoring relationships

While Big Brothers Big Sisters supports the Administration's position of only funding effective programs going forward, we have proposed partnering with the Department of Education to ensure that existing grantees do not have to prematurely close any current mentoring relationships. We understand that the cost of honoring the last class of grants which were awarded in Fiscal Year 2008 would require Congress to provide \$17 million for the program in Fiscal Year 2010.

#### **Amachi (Mentoring Children of Prisoners)**

An estimated 2.4 million children have an incarcerated parent – and BBBS' *Amachi* program addresses this critical need. The goal of *Amachi* is to demonstrate that the best way to stop the vicious cycle of substance abuse, delinquency and incarceration among children of incarcerated parents is to give the children what they need the most - a supportive and stable adult who will help them discover their own strengths, abilities and resistance skills. Volunteers for the program are recruited through their congregations and matched with at-risk children and youth, spending time each week with the child to gradually build a supportive relationship. Research has shown that children and youth of incarcerated parents are at higher risk of child abuse, neglect, illiteracy, drug and alcohol abuse, crime, violence, and premature death than are their peers. A BBBS mentor in the life of an at-risk child can dramatically reduce a child's chance of falling prey to these risks. We respectfully request level funding for the "Mentoring Children of Prisoners" program in Fiscal Year 2010.

#### **Volunteer Generation Fund (Corporation for National Service)**

In the wake of President-elect Obama's "call to service" in January, also known as National Mentoring Month, Big Brothers Big Sisters saw a significant increase in volunteer applications. As the economic crisis deepens, these Big Brothers and Big Sisters will be helping to meet the critical demand our disadvantaged youth have for friendship, especially during these challenging times. There is an interest among Americans to serve the community and Big Brothers Big Sisters is anxious to harness this hope. The bipartisan citizen service legislation signed in to law by President Obama on April 21<sup>st</sup> will expand opportunities for citizens to serve, will direct this service toward the nation's most urgent challenges, and provides Congress the change to invest in new and innovative solutions to our most persistent social problems. In particular, Big Brothers Big Sisters respectfully requests that \$50 million for the Volunteer Generation Fund in Fiscal Year 2010 to spur innovation in volunteer recruitment and management.

As we all work to change how our children grow up in America, Big Brothers Big Sisters is your proud partner.



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*Creating a better future through brain injury prevention, research, education and advocacy*

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May 1, 2009

The Honorable Dave Obey  
Chairman  
House Appropriations Subcommittee on Labor,  
Health and Human Services, Education and Related Agencies  
2358 Rayburn House Office Building  
Washington, DC 20515

The Honorable Todd Tiahrt  
Ranking Member  
House Appropriations Subcommittee on Labor,  
Health and Human Services, Education and Related Agencies  
1016 Longworth House Office Building  
Washington, DC 20515

Dear Mr. Chairman Obey and Ranking Member Tiahrt:

Thank you for the opportunity to submit this written testimony with regard to the FY 2010 Labor-HHS-Education appropriations bill. My testimony is on behalf of the Brain Injury Association of America (BIAA), our national network of state affiliates, and hundreds of local chapters and support groups from across the country.

A traumatic brain injury (TBI) is a blow or a jolt to the head that temporarily or permanently disrupts brain function – i.e. who we are and how we think, act, and feel. In the civilian population alone every year, more than 1.5 million people sustain brain injuries from falls, car crashes, assaults and contact sports. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

And now we are seeing an increasing number of servicemembers returning from the conflicts in Iraq and Afghanistan with TBI, which has been termed one of the signature injuries of the War. A recent study conducted by the RAND Corporation found that 320,000 troops, or 19% of all servicemembers, returning from Operations Enduring Freedom and Iraqi Freedom may have

experienced a traumatic brain injury during deployment. Many of these returning servicemembers are undiagnosed or misdiagnosed and subsequently they and their families will look to community and local resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into the community.

For the past 12 years Congress has provided minimal funding through the HRSA Federal TBI Program to assist States in developing services and systems to help individuals with a range of service and family support needs following their loved one's brain injury. Similarly, the grants to state Protection and Advocacy Systems to assist individuals with traumatic brain injuries in accessing services through education, legal and advocacy remedies are woefully underfunded. Rehabilitation, community support and long-term care systems are still developing in many States, while stretched to capacity in others. Additional numbers of individuals with TBI as the result of war-related injuries only adds more stress to these inadequately funded systems.

BIAA respectfully urges you to provide States with the resources they need to address both the civilian and military populations who look to them for much needed support in order to live and work in their communities.

With broader regard to all of the programs authorized through the TBI Act, BIAA specifically requests:

- **\$11 million** for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Prevention and National Public Education/Awareness;
- **\$20 million** for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program; and
- **\$6 million** for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program.

The TBI Act Amendments of 2008, authorizes the HHS, Health Resources and Service Administration (HRSA) to award grants to (1) states, American Indian Consortia and territories to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past twelve years the HRSA Federal TBI State Grant Program has supported state efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions

In FY 2009, HRSA reduced the number of state grant awards to 15, in order to increase each monetary award from \$118,000 to \$250,000. This means that many states that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increasing the program to \$20 million will provide funding necessary for each state including the District of Columbia, the American Indian Consortium to sustain and expand state service delivery; and to expand the use of the grant funds to pay for such services as Information &

Referral (I&R), service coordination and other necessary services and supports identified by the state.

Similarly, the HRSA TBI P&A Program currently provides funding to all state P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services.

Effective Protection and Advocacy services for people with a traumatic brain injury leads to reduced government expenditures and increased productivity, independence and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. A \$6 million appropriation would trigger a formula that would ensure that each P&A can provide a significant PATBI program with appropriate staff time and expertise.

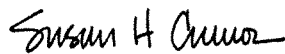
Funding for the TBI Model Systems is urgently needed to ensure that the nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a "proving ground" for future researchers.

In order to make this program more comprehensive, Congress should provide **\$13.3 million** in FY 2010 funding for NIDRR's TBI Model Systems of Care Program, in order to add four new centers and two collaborative research projects. In addition, given the national importance of this research program, the TBI Model Systems of Care program should receive "line-item" status within the broader NIDRR budget.

We ask that you consider favorably these requests for the HRSA Federal TBI Program, NIDRR TBI Model Systems Program and for Centers for Disease Control and Prevention (CDC) to gather needed data, shepherd public awareness, education, and prevention programs; as well as the sustain and bolster TBI Model Systems that conduct vital research.

Sincerely,



Susan H. Connors, President/CEO  
Brain Injury Association of America

## CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COALITION

c/o American Public Health Association

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(202) 777-2514

### Testimony of the CDC Coalition

Concerning the Centers for Disease Control and Prevention's Budget for Fiscal Year 2010  
House Appropriations Subcommittee on Labor, Health and Human Services and Education  
Submitted for the Record  
May 1, 2009

The CDC Coalition is a nonpartisan coalition of more than 100 groups committed to strengthening our nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, clinicians, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency—not just the individual programs that it funds. In the best judgment of the CDC Coalition – given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs and our many unmet public health needs and missed prevention opportunities – **we believe the agency will require funding of at least \$8.6 billion for CDC's "core programs"**. This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).

The CDC Coalition appreciates the Subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, and environmental health programs at CDC. We also appreciate the support you provided in the economic recovery legislation for public health and prevention and wellness funding. By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. Ensuring a strong CDC is especially important given the important role CDC will play as Congress considers legislation to reform the nation's health system.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak. This has been demonstrated most recently by CDC's quick response and ongoing investigation into human infections with H1N1 flu (swine flu) in the United States and internationally.

CDC's budget has actually shrunk since 2005 in terms of real dollars. According to an analysis by the Campaign for Public Health, had CDC's budget for its core programs kept up with inflation, it would be more than \$6.8 billion – about \$220 million more than the amount appropriated for CDC in the FY 2009 Omnibus bill. We are grateful for the \$239 million increase in FY 09, but we have a long way to go especially in these challenging times when public health is being asked to do more, not less. We must make up the lost ground and fully fund CDC's core public health programs at a

time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

### **The Multiple Roles of the CDC**

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for state and local capacity grants. We ask the Subcommittee to ensure that our states and local communities can be prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Public health programs delivered at the state and local level should be flexible to respond to state and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. We greatly appreciate the Subcommittee's past support for this program and we urge your continued support so that states can tailor federal public health dollars to meet their specific needs.

### **Addressing Urgent Realities**

Heart disease remains the nation's No. 1 killer. In 2006, more than 631,000 people in the United States died from heart disease, accounting for nearly 26% of all U.S. deaths. Of those who died from heart disease, 50% were women. Stroke is the third leading cause of death and is a leading cause of disability. In 2006, stroke killed more than 137,000 people (60% of them women), accounting for about 1 of every 18 deaths. In 1998, the U.S. Congress provided funding for CDC to initiate a national, state-based Heart Disease and Stroke Prevention Program with funding for eight states. Now, 31 states and the District of Columbia are funded, 27 as capacity building and 14 as basic implementation. We must expand these efforts to continue the gains we have made in combating heart disease and stroke.

The CDC funds proven programs addressing cancer prevention, early detection, and care. Cancer is the second most common cause of death in the United States. In 2008, more than 1.4 million new cases of cancer will be diagnosed, and about 565,650 Americans— more than 1,500 people a day—are expected to die of the disease. The financial cost of cancer is also significant. According to the National Institutes of Health (NIH), in 2007 the overall cost for cancer in the United States was more than \$219 billion: \$89 billion for direct medical costs, \$18.2 billion for lost worker productivity due to illness, and \$112 billion for lost worker productivity due to premature death.

Among the ways the CDC is fighting cancer, is through funding the National Breast and Cervical Cancer Early Detection Program that helps low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to states to develop Comprehensive Cancer Control (CCC) plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and implement specific cancer prevention and control activities customized to address each state's particular needs. CDC also funds programs to raise awareness about colorectal, prostate, lung, ovarian and skin cancers, and the National Program of Cancer Registries, a critical registry for tracking cancer trends in all 50 states.



Chronic Obstructive Pulmonary Disease (COPD) – which includes emphysema and chronic bronchitis – is the fourth leading cause of death in the U.S. More than 12 million U.S. adults have been diagnosed with COPD, but an equal number are believed to have the disease but have not yet been diagnosed. In its FY09 Congressional Justification, CDC expressed interest in “developing a roadmap to explore the public health issues related to COPD.” We ask the Subcommittee to support the development of the initial assessment and planning of such a roadmap with a specific appropriation.

Although more than 23 million Americans have diabetes, over 6 million cases are undiagnosed. From 1980-2007, the number of people with diabetes in the United States more than quadrupled, from 5.8 million to 23.6 million. Each year, more than 20,000 people with diabetes become blind, more than 43,000 develop kidney failure, and about 84,000 have leg, foot, or toe amputations. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers. Unfortunately funding for diabetes, along with many other core CDC programs, has either been cut or flat funded for the past several years. Without additional funds, most states will not be able to create programs based on these new data. States also will continue to need CDC funding for diabetes control programs that seek to reduce the complications associated with diabetes.

Over the last 25 years, obesity rates have doubled among adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The CDC funds programs to encourage the consumption of fruits and vegetables, to get sufficient exercise, and to develop other habits of healthy nutrition and activity. In order to fully support these activities, we urge the Subcommittee to provide adequate funding for CDC’s Division of Nutrition and Physical Activity and Healthy Communities Program.

More than 400,000 people die prematurely every year due to tobacco use. CDC’s tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

Each day more than 3,600 young people initiate cigarette smoking. At the same time, according to CDC, only 3.8% of elementary schools, 7.9% of middle schools and 2.1% of high schools provide daily physical education or its equivalent for the entire school year. Twenty-two percent of schools do not require students to take any physical education at all. Almost 90% of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30% of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and nearly 4 million teens are infected with a sexually transmitted disease. School health programs, funded through CDC’s Division of Adolescent and School Health, are one of the most efficient means of correcting these problems, shaping our nation’s future health, education, and social well-being.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. The CDC estimates that about 1.1 million Americans are living with HIV, 21 percent of who are unaware of their infection. Also, the number of people living with HIV is increasing, as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed over 550,000 in the U.S. and is devastating populations around the globe. CDC’s HIV prevention efforts must be expanded.

The United States has the highest sexually transmitted diseases (STD) rates in the industrialized world. More than 19 million people contract STDs each year. CDC estimates that STDs cost the U.S. healthcare system as much as \$15.3 billion annually in 2007. Elimination of STDs, especially syphilis, is now within our grasp. These welcome opportunities, if adequately funded now, will save millions in annual health care costs in the future. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. State and local STD control programs depend heavily on CDC funding for their operational support.

CDC and its National Center for Health Statistics (NCHS) conduct several surveys that help track health risks and provide information for priority setting at the state and local levels. The Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey (NHANES) are important national sources of objective health data. NHANES is a unique collaboration between CDC's NCHS, NIH, and others to obtain data for biomedical research, public health, tracking of health indicators, and policy development. Mobile exam centers travel throughout the country to collect data on chronic conditions, nutritional status, medical risk factors (e.g., high cholesterol level, obesity, high blood pressure), dental health, vision, illicit drug use, blood lead levels, food safety, and other factors that are not possible to assess by use of interviews alone. Ensuring adequate funding for NHANES and other surveys and health data collection activities is essential for determining rates of major diseases and health conditions and developing public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Our members are committed to ending the disparities. We encourage the Subcommittee to provide adequate funds for CDC's REACH program.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save health care costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination and significant racial and ethnic disparities in vaccination levels persist among the elderly. Childhood immunization programs at CDC also need a funding boost, to ensure sufficient purchase and delivery of the varicella and pneumococcal vaccines. In addition, developing functional immunization registries in all states will be less costly in the long run than maintaining the incomplete systems currently in place.

Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on seven vaccines recommended in the childhood series, \$16.50 is saved in direct and indirect costs. An estimated 10 million cases of vaccine avertable diseases and 33,000 deaths are prevented each year through timely immunization. Despite the incredible success of the program, it faces serious financial challenges. We thank the Subcommittee for its support for including Section 317 funds in the economic recovery legislation and we ask that you work to fully fund the program in order to cover all who are currently underserved by the program.

Unintentional injuries are the leading cause of death in the United States for people ages 1-44. In December, 2007, the CDC released the results of a study of injury deaths. Following a 25-year decline in injury mortality rates, there was a 5.5% increase in injury mortality from 1999 to 2004. Newly available 2005 data shows an even greater increase - 8.2% - with 173,753 reported injury

deaths in the U.S. Add injury-related disability, both short- and long-term, hospitalizations and emergency department visits and the economic burden of medical treatment and lost productivity totals over \$406 billion.

In addition to unintentional injuries, approximately 1.5 million women are raped and/or physically assaulted by an intimate partner each year. A study released by the CDC found that the average health care cost for women exceeds twice the average cost for men. In an effort to increase the opportunities for prevention of violence and reduce health care costs, we urge you to include increased funding to focus on prevention of domestic and sexual violence through state level partnerships between maternal and child health, community health programs, and domestic and sexual violence advocates. It is clear that we have a growing public health problem on both fronts, and we urge an increase in funding for injury prevention and control programs, including CDC's National Violent Death Reporting System.

Of the four million babies born each year in the United States, one in every 33 is born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20% of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. An estimated 54 million people in the U.S currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. Direct and indirect costs associated with disability exceed \$300 billion.

Created by the Children's Health Act of 2000 (P.L. 106-310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities.

We also encourage the Subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. The agencies that carry out these services are fragmented and their resources are stretched. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, E. coli and lead in drinking water. We encourage the Committee to provide additional funding for CDC's Environmental Health Laboratory and the National Environmental Health Outcome Tracking Network. We ask that the Subcommittee continue its recent efforts to expand and enhance CDC's capacity to help the nation prepare for and adapt to the potential health effects of climate change. Expanded funding would allow CDC to: establish a research coordinating center and act as the lead agency to pull together a coordinating work group on climate change and health research; create a federal Interagency Task Force on Climate Change and Health to assess the public health implications of major climate, energy, transportation, agricultural, and other sectoral policies; develop preparedness strategies for climate change tailored to local hazards and local needs; and fund academic "Centers of Excellence" at universities to conduct climate change and health research.

We appreciate the Subcommittee's hard work in advocating for CDC programs in a climate of competing priorities. We thank you for considering our FY 2010 request for **\$8.6 billion** for CDC's "core programs".

**Members of the CDC Coalition**

- Academy Health
- Advocates for Youth
- AIDS Action
- AIDS Alliance for Children, Youth and Families
- AIDS Foundation of Chicago
- Allergy and Asthma Network Mothers of Asthmatics
- Alliance for Healthy Homes
- Alliance to End Childhood Lead Poisoning
- American Academy of Ophthalmology
- American Academy of Orthopaedic Surgeons
- American Academy of Pediatrics
- American Alliance for Health, Physical Education, Recreation and Dance
- American Association for Health Education
- American Association of Colleges of Pharmacy
- American Association of Geriatric Psychiatry
- American Association of Medical Colleges
- American Cancer Society
- American College of Clinical Pharmacy
- American College of Obstetricians and Gynecologists
- American College of Preventive Medicine
- American College of Occupation and Environmental Medicine
- American Dental Education Association
- American Dietetic Association
- American Foundation for AIDS Research
- American Heart Association
- American Lung Association
- American Podiatric Medical Association
- American Psychological Association
- American Psychological Society
- American Public Transportation Association
- American Red Cross
- American School Health Association
- American Society for Gastrointestinal Endoscopy
- American Society for Microbiology
- American Society for Reproductive Medicine
- American Society of Clinical Pathologists
- American Thoracic Society
- American Urological Association
- American Public Health Association
- Association for Professionals in Infection Control and Epidemiology
- Association for Psychological Science
- Association of Maternal and Child Health Programs
- Association of Minority Health Profession Schools
- Association of Prevention Teaching and Research
- Association of Public Health Laboratories
- Association of Reproductive Health Professionals
- Association of Schools of Public Health
- Association of State and Territorial Chronic Disease Program Directors
- Association of State and Territorial Directors of Nursing
- Association of State and Territorial Health Officials
- Brain Injury Association of America
- Campaign for Public Health
- Campaign for Tobacco Free-Kids
- Center for Science in the Public Interest
- Center for the Advancement of Health
- Coalition for Health Funding
- Coalition for Health Services Research
- Commissioned Corps officers of the U.S. Public Health Service
- Community HIV/AIDS Mobilization Project
- Consortium for Citizens with Disabilities
- Consortium of Social Science Associations
- Council of State and Territorial Epidemiologists
- Crohn's and Colitis Foundation of America
- Easter Seals
- Emergency Nurses Association
- Epilepsy Foundation
- Every Child by Two
- Families USA
- Gay and Lesbian Medical Association
- Guttmacher Institute
- Healthcare for the Homeless
- Hepatitis Foundation International
- National Hemophilia Foundation
- Home Safety Council
- Immune Deficiency Foundation
- Infectious Disease Society of America
- March of Dimes
- National Alliance of State and Territorial AIDS Directors

- National Association of Children's Hospitals and Related Institutions
- National Association of Councils on Developmental Disabilities
- National Association of County and City Health Officials
- National Association of Local Boards of Health
- National Association of School Nurses
- National Association of State Emergency Medical Services Directors
- National Association of State EMS Officials
- National Athletic Trainer's Association
- National Black Nurses Association
- National Coalition for LGBT Health
- National Coalition of STD Directors
- National Council of La Raza
- National Episcopal AIDS Coalition
- National Family Planning & Reproductive Health Association
- National Health Care for the Homeless Council
- National Latino Council on Alcohol and Tobacco Prevention
- National Medical Association
- National Minority AIDS Council
- National Network for Youth
- National Recreation and Park Association
- National Rural Health Association
- Partnership for Prevention
- Planned Parenthood Federation of America
- Research!America
- Safe Kids USA
- Sexuality Information and Education Council of the United States
- Society for Healthcare Epidemiology
- Society for Maternal/Fetal Medicine
- Society for Public Health Education
- Society of Hospital Medicine
- Society of State Directors of Health, Physical Education and Recreation
- Spina Bifida Association of America
- The AIDS Institute
- Tourette Syndrome Association
- Trust for America's Health
- United Cerebral Palsy
- US Conference of Mayors
- YMCA of the USA
- WomenHeart: The National Coalition for Women with Heart Disease



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**Testimony submitted to the**  
**Subcommittee on Labor, Health & Human Services, Education and Related Agencies**  
**House Committee on Appropriations**  
**Appropriations for Fiscal Year 2010**  
**April 28, 2009**

The Children's Environmental Health Network (the Network) appreciates this opportunity to comment on the FY 2010 appropriations to the Departments of Health & Human Services and Education for activities that protect children from environmental hazards.

The Network appreciates the wide range of priorities that you must consider for funding. We urge you to give priority to those programs that directly protect and promote children's environmental health. In so doing, you will improve not only our children's health, but also their educational outcomes and their future.

The Network is a national organization whose mission is to promote a healthy environment and to protect the fetus and the child from environmental health hazards. We recognize that children, in our society, have unique moral standing. The Children's Environmental Health Network was created to promote the incorporation of basic pediatric facts such as these in policy and practice:

- Children's bodies and behaviors differ from adults. In general, they are more vulnerable than adults to toxic chemicals.
- Children are growing. Pound for pound, children eat more food, drink more water and breathe more air than adults. Thus, they are likely to be more exposed to substances in their environment than are adults. Children have higher metabolic rates than adults and are different from adults in how their bodies absorb, detoxify and excrete toxicants.
- Children's systems, including their nervous, reproductive, digestive, respiratory and immune systems, are developing. This process of development creates periods of vulnerability when toxic exposures may result in irreversible damage when the same exposure to a mature system may result in little or no damage.
- Children behave differently than adults, leading to a different pattern of exposures to the world around them. For example, they exhibit hand-to-mouth behavior, ingesting whatever substances may be on their hands, toys, household items, and floors. Children play and live in a different space than do adults. For example, very young children spend hours close to the ground where there may be more exposure to toxicants in dust, soil, and carpets as well as low-lying vapors such as radon, mercury vapor or pesticides.
- Children have a longer life expectancy than adults; thus they have more time to develop diseases with long latency periods that may be triggered by early environmental exposures, such as cancer or Parkinson's disease.

Clear, sound science underlies these principles. A solid consensus in the scientific community supports these concepts. The world in which today's children live has changed tremendously from that of previous generations. There has been a phenomenal increase in the substances to which children are exposed. According to the EPA, more than 83,000 industrial chemicals are currently produced or imported into the United States. Thousands of chemicals are ubiquitous in our environment worldwide. Traces of hundreds of chemicals are found in all humans and animals. Every day, children are exposed to a mix of chemicals, most of them untested for their effects on developing systems.

We urge the Committee to provide the necessary resources for the Federal programs and activities that help to protect children from environmental hazards. The key programs that are in your jurisdiction are listed below.

#### **Centers for Disease Control and Prevention (CDC) and the National Environmental Health Center (NEHC)**

The Network strongly supports the work of the CDC and the NEHC, especially NEHC's efforts to continue and expand its **biomonitoring program** and to continue its **national report card on exposure information**, using the highly-respected National Health and Nutrition Examination Survey (NHANES). A vital CDC responsibility in pediatric environmental health is to assist in filling the major information gaps that exist about children's exposures.

The Network supports a funding level of \$8.6 billion for CDC's core programs in FY 2010. The Network urges the Committee to provide an additional \$19.6 million for CDC's Environmental Health Laboratory in FY 2010. These funds would be used to support state public health laboratory biomonitoring capabilities, to increase the number of chemicals CDC measures, to provide training and quality assurance to the state laboratories awarded biomonitoring funds, among other activities. The Network believes it is especially critical for the NEHC to gather and publish expanded information in the report card on children's exposures.

#### **Public health tracking**

The CDC's National Environmental Public Health Tracking Program helps to track environmental hazards and the diseases they may cause, coordinating and integrating local, state and Federal health agencies' collection of critical health and environmental data. We urge the Committee to provide \$50 million for the tracking network in FY 2010 to expand it to additional states and support the continued development of a sustainable, nationwide Network.

Additionally, data on children's "real world" exposure and disease are critically needed. Since children spend hours every day in school and child care, we urge you to direct the Tracking Program to include grants for pilot methods for tracking children's health in schools and child care settings.

#### **Global Climate Change**

We strongly urge the Committee to designate \$50 million for the CDC to help the public prepare for and adapt to the potential health effects of **global climate change** in FY2010.

Global climate change presents major challenges to public health. **Children, as a vulnerable subpopulation, are among those at greatest risk of harm.** Children in communities that are already disadvantaged will be the most harmed. Recent studies have detailed how children's physical and social health may be harmed, ranging from respiratory diseases and melanoma (due to atmospheric changes), to gastrointestinal diseases (due to increased water contamination), to an increased range for some diseases (malaria, dengue, encephalitides, Lyme disease), to increased rates of malnutrition (due to severe drought and severe precipitation), to the harm caused by displacement, water and food insecurity, and forced migration (caused by drought, increased rain and severe storms, and rising sea levels) and the resulting international conflict and political unrest.

It is imperative that the Federal government undertake efforts to mitigate and adapt to climate change. Providing funding to the CDC for preparing for the potential health effects of global climate change is an important step.

**National Institute of Environmental Health Sciences (NIEHS)  
Children's Environmental Health Research Centers of Excellence**

NIEHS is a vital institution in our efforts to understand how to protect children, whether it is identifying and understanding the impact of substances that are endocrine disruptors, or better understanding childhood exposures that may not affect health until decades later, or seeking answers to many other important questions.

The Children's Environmental Health Research Centers, funded by NIEHS and the U.S. EPA, play a key role in providing the scientific basis for protecting children from environmental hazards. With budgets of \$1 million per year per center (unchanged over more than 10 years), this program generates valuable research. A unique aspect of these Centers is the requirement that each Center actively involves its local community in a collaborative partnership, leading both to community-based participatory research projects and to the translation of research findings into child-protective programs and policies. Researchers have chosen to participate in the center funding mechanism because of the ability to do interdisciplinary research, to break ground in a relatively new field and to be involved in the community – all things that are not easy to do using other grant mechanisms. The scientific output of these centers has been outstanding. For example, four of the Centers had findings that clearly showed that prenatal exposure to a widely-used pesticide affected developmental outcomes at birth and early childhood. This was important information to EPA's policy makers in their consideration of this pesticide. Another recent example is the finding of a biomarker in newborns for childhood leukemia, firmly establishing the important role of prenatal environment factors in causation of this disease.

Unfortunately, almost all of the existing 12 centers are currently operating on no-cost extensions. We strongly support the center concept and the value of a network of centers. We also support current efforts by NIEHS and the EPA to competitively renew and to expand this valuable



program by adding four formative centers. However, only five of the existing centers are to be renewed. If centers are shuttered, we will lose access to valuable populations such as children with asthma or growing up with pesticide exposure in farm communities. We will lose the ability to learn about issues like early puberty concerns, exposures in school settings, and pre-adolescent and adolescent outcomes.

Thus, we urge the Committee to appropriate at least \$15 million for the NIEHS share of funding so that, in concert with the EPA contribution, an adequate number of centers (old and new) will have funding in FY2010.

In addition, the Network urges the Committee to support NIEHS by increasing its overall budget, and that of the Superfund research program, by 5% over last year's level and directing that included in this increase would be a \$5 million increase specifically for research on children's environmental health issues. The Superfund research program has supported some vital children's research but funding has been level over the last 4 years. .

#### **National Children's Study (NCS)**

The National Children's Study is examining the effects of environmental influences on the health and development of more than 100,000 children in 105 communities across the United States, following them from before birth until age 21. The NCS will be one of the richest research efforts ever geared toward studying children's health and development and will form the basis of child health guidance, interventions, and policy for generations to come. The Study will provide a better understanding of how children's genes and their environments interact to affect their health and development, thus improving the health and well-being of all children.

Enrollment in the study began this January, after eight years of planning and development. The Network urges the Committee to continue its enthusiastic support for the Study in this and future years, including full funding of \$195 million in FY2010.

The Network also asks the Committee to direct the National Institute of Child Health and Human Development to assure that protocols are in place for measuring exposures in the child care and school settings. The Network believes it is critically important to understand how school and child care exposures differ from home exposures very early in the NCS.

#### **Pediatric Environmental Health Specialty Units (PEHSU)**

A key, but dramatically underfunded, program is the Pediatric Environmental Health Specialty Unit (PEHSU) network. Funded by the Agency for Toxic Substances and Disease Registry and the U.S. EPA, the PEHSUs form a network with a center in each of the U.S. Federal regions, plus one center in Canada and one in Mexico. PEHSU professionals provide quality medical consultation for health professionals, parents, caregivers, and patients.

Last year, the entire program, covering the ten U.S. centers, received less than \$2 million. Each center received only \$120,000. These centers have done tremendous work on these small

budgets. We urge the Committee to provide funding for this program in FY 2010 at the level of \$200,000 per center.

#### **School Environmental Health**

Each school day, about 54 million children and 7 million adults spend a full week inside schools. Unfortunately, many of the nation's public and private school facilities are shoddy or even "sick" buildings whose environmental conditions harm children's health and undermine attendance, achievement, and productivity. In 1996, GAO reported that more than 13 million children were compelled to be in schools that threatened their health and safety. Two Federal statutes that would create a foundation for healthy schools are already in place, authorizing the U.S. Department of Education and the EPA to address school environments. Unfortunately, to date neither of these programs have been funded.

We strongly urge the Committee to provide the \$25 million authorized by the Healthy and High Performance Schools Act (P.L. 107-110) to the grant program for state agencies to develop and disseminate information and assistance on high performance school design standards. The Committee should also direct the Department of Education to conduct a National Priority Study, as required under HHPS, on the impacts of decayed facilities on children and to report to Congress. To date, Education has only produced a brief review of the scientific literature.

These programs and activities are especially vital in light of the "stimulus" funds for school modernization or renovation. The stimulus bill does not require consideration of environmental health or children's health and safety. Yet, without specific consideration of health, steps to "green" a school -- such as increasing insulation at a school to improve energy efficiency -- can have unintended harmful side effects, such as creating or exacerbating indoor air quality problems.

#### **Child Care Environmental Health**

Thirteen million preschoolers— 60% of young children —are in child care. Millions of preschoolers -- our youngest and most vulnerable population -- enter care as early as six weeks of age and can be in care for more than 40 hours per week. Yet little is known about the environmental health status of our child care centers nor how to assure that they are protecting this important group of children. The Network is working to correct these gaps.

We ask the Committee to direct the HHS Assistant Secretary for Children and Families to report on the Administration for Children and Families (ACF) activities that protect children from environmental hazards in child care settings, especially in the Office of Head Start.

In conclusion, investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures, an outcome we can all support. That is why the Network asks you to give priority to these programs.

Thank you for the opportunity to testify on these critical issues.

**Testimony Of  
TIMOTHY S. DAVIS  
PRESIDENT AND CEO  
CLOSE UP FOUNDATION  
Before the  
HOUSE APPROPRIATIONS  
SUBCOMMITTEE on  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION and  
RELATED AGENCIES  
Contact: [seth.maiman@closeup.org](mailto:seth.maiman@closeup.org), 703/706-3478  
May 1, 2009**

Mr. Chairman, my name is Timothy S. Davis, President and CEO of the Close Up Foundation and I submit this testimony in support of our \$5 million appropriations request for the Close Up Fellowship Program that is funded through a grant from the Department of Education, Office of Innovation and Improvement.

Close Up Foundation is a nonprofit, nonpartisan civic education organization dedicated to the idea that, within a democracy, informed, active citizens are essential to a responsive government. Close Up's mission is to inform, inspire, and empower students and their teachers to exercise their rights and accept the responsibilities of citizens in a democracy. Close Up's experiential methodology emphasizes that democracy is not a spectator sport, and provides young people with the knowledge and skills to participate in the democratic process.

Close Up fulfills its mission with exciting, hands-on programs for students and their teachers in Washington. Close Up uses the city as a living classroom, giving students unique access to the people, processes and places that make up our nation's capital. Our students are a diverse group – coming from every state and beyond and from all walks of life. Over 650,000 have graduated from our experiential programs.

Three core principles of Close Up are: 1) family income should not be a barrier to a students' participation, 2) commitment to diversity – outreach should reach a broad cross section of young people, and 3) enrollment should be open to all students, not just student leaders or high academic achievers.

The Close Up Fellowship Program provides for financial assistance to economically disadvantaged students and their teachers to participate on week-long Close Up Washington civic education programs. The Fellowship Program, authorized in federal law since 1972 and currently under Section 1504 of the No Child Left Behind Act, has been continuously funded through a U.S. Department of Education grant for over thirty-five years. The program provides financial assistance to economically disadvantaged high school and middle schools students and their teachers. Close Up

makes every effort to ensure the participation of students from rural, small town and urban areas and gives special consideration to students with special educational needs, including students with disabilities, ethnic minority students, and students with migrant parents. Student fellowships recipients are selected by their schools and must qualify according to the income eligibility guidelines established by Close Up.

Close Up Fellowship Program recipients participate in Close Up Washington civic education programs with all other Close Up participants. Student fellowship recipients participate in the Washington High School Program, the Washington Middle School, and the Program for New Americans. There is no special programming for Fellowship recipients nor are they identified or singled out in any manner. Fellowship recipients add diversity to the student body on Close Up programs. The fellowship program thus benefits not only the recipient but all Close Up student program participants.

Close Up provides a federal fellowship to a select group of teachers who work with economically disadvantaged students on a Close Up program. Close Up teachers participate in the Close Up Program for Educators, a program which “trains the trainers”. Teachers take ideas and methodologies for teaching and engaging young people in civic activities and put them to use in their schools and communities.

The teacher is the essential link to reaching students of diverse backgrounds. Close Up believes that any effort to improve and promote civic involvement among young people must begin with inspired and well-prepared teachers. It is from this inspired corps of teachers that a multiplier effect in civic learning and engagement is produced. Teachers who participate in the teacher program leave inspired and informed and convey a similar attitude to their students. In a recent survey of teachers who participated on the Close Up Program for Educators in March and April of 2009, 95% of the teachers who responded indicated that they returned to their schools feeling “inspired and reinvigorated” after completing the Close Up program.

Close Up is grateful to the United States Congress for its long-standing support of the Close Up Fellowship Program through the appropriations process. Tens of thousands of young people have been able to participate on Close Up Washington civic education programs as a result of the federal funding.

Close Up’s FY10 request is based in its desire to significantly increase the number of economically disadvantaged young people who participate on Close Up Washington civic education programs. The funds, which assist the disadvantaged and provide seed money for at-risk schools and communities to participate on these life transforming programs, are more important now than ever. Given the economic climate it will be more challenging for communities to raise the necessary funds for participation on Close Up programs. The federal funding bridges that gap and Close Up feels that with aggressive outreach into economically distressed communities we can continue to provide these experiences to our young people.

Close Up civic education programs also fill a gaping hole in the civic education of our nation's youth. In a recent survey of high school teachers, 83% reported that emphasis on standardized tests has made it difficult to teach practical citizenship skills in the classrooms. As the teaching of social studies and civics has given way to math and science, programs like Close Up become an even more important supplement to classroom teaching.

Close Up's appropriations request reflects the increasing cost of providing these important Washington programs. The cost of airfare, accommodations, food and local transportation skyrocketed during the decade the Close Up Fellowship funding remained flat at under \$1.5 million. The increase in the appropriations amount to \$1.942 million in FY08 has helped combat a small portion of those increased costs but still results in a sharp decrease in the number of economically disadvantaged students that Close Up has been able to serve. We believe that during hard economic times it is even more imperative for the federal government to invest in the civic education of young people. And, by investing in a Close Up education, the government also greatly supports economic sectors such as transportation and hospitality which are suffering in the downturn.

Members of Congress have the opportunity to meet with Close Up groups from their districts during Close Up "Capitol Hill Day". You see the excitement and pride as our students gain confidence to express their views on the public policy issues that most directly affect their lives. Through their workshops, seminars and experience of being in Washington, Close Up instills these students with the knowledge and skills to become active citizens in our democracy.

Many of your constituents would not be able to participate in this life altering program without the benefit of the Close Up Fellowship Program. There is no better investment that we can make in our nation's future than in building educated and responsible citizens, one person at a time.

*Close Up respectfully requests that the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Services appropriate \$5 million for the Close Up Fellowship Program.*

## COALITION FOR HEALTH SERVICES RESEARCH

W. David Helms, Ph.D.  
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The Coalition for Health Services Research is pleased to offer this testimony regarding the role of health services research in improving our nation's health. The Coalition's mission is to support research that leads to accessible, affordable, high-quality health care. As the advocacy arm of AcademyHealth, the Coalition represents the interests of 3,500 researchers, scientists, and policy experts, as well as 150 organizations that produce and use health services research.

Health care in the United States has the potential to improve people's health dramatically, but often falls short and costs too much. Health services research is used to understand how to better finance the costs of care, measure and improve the quality of care, and improve coverage and access to affordable services. It provides patients, providers, payers, and policymakers with the necessary tools to make health care:

- **Affordable**, by decreasing cost growth to sustainable levels.
- **Efficient**, by decreasing waste and overpayment and monitoring cost effectiveness of care.
- **Safe**, by decreasing preventable medical errors, monitoring public health, and improving preparedness.
- **Effective**, by evaluating programs and outcomes and promoting evidence-based innovations.
- **Equitable**, by eliminating disparities in health and health care.
- **Accessible**, by connecting people with the health care they need when they need it.
- **Patient-centered**, by increasing patient engagement in, and satisfaction with, the care they receive.

Indeed, health services research is changing the face of American health care, uncovering critical challenges facing our nation's health care system. For example, the 2000 Institute of Medicine (IOM) report *To Err is Human* found that up to 98,000 Americans die each year from medical errors in the hospital. Health services research also uncovered that disparities and lack of access to care in rural and inner cities result in poorer health outcomes. And, it found that obesity accounts for more than \$92 billion in medical expenditures each year and has worse effects on chronic conditions than smoking or problem drinking.

But health services research does not just lift the veil on problems plaguing American health care; it also seeks ways to address them. Health services research framed the debate over health care reform in Massachusetts—forming the basis for that state's 2006 health reform legislation—and continues to frame the debate on the national stage today. It offers guidance on implementing and making the best use of health information technology, and getting the best care at the best value across a menu of treatment options.

In fact, there are increasing examples that demonstrate how comparative effectiveness research—an emerging science in the broader field of health services research—provides the scientific basis needed to determine what treatments work best, for whom, and in what circumstances.

- The Agency for Healthcare Research and Quality (AHRQ) found that drugs can be as effective as surgery in management of gastroesophageal reflux disease (GERD)—where stomach acid enters the esophagus, causing heartburn and potential esophageal damage. GERD is one of the most common health conditions among older Americans and results in \$10 billion annually in direct health care costs. Knowing that, for the majority of patients, drugs can be as effective as surgery in relieving the symptoms could result in significant health care savings and improved quality of life.
- The National Institute of Mental Health (NIMH) found that, within a class of antipsychotic drugs, the older, less expensive drug (Perphenazine) was just as effective and caused no worse side effects than the three newer, more expensive drugs in treating patients with schizophrenia. One of the newer drugs (Zyprexa) was slightly more effective in controlling systems than the other drugs, but at the cost of serious side effects.<sup>1</sup> This study enables greater flexibility in care and informs patients and providers about costs and quality of care.

As these examples suggest, health services research can contribute greatly to better health care at better value. It is a true public good, providing a basis for improvements in our health care system that will benefit the general public. Americans overwhelmingly agree. A recent opinion survey commissioned by Research!America found that 95 percent of Americans say it is important to support research focused on how well our health care system is functioning. After all, the investment in basic research and the development of new medicines and equipment is wasted if the health system cannot safely and effectively deliver that care.

For the last six years, the Coalition has been collecting data to track the federal government's expenditures for health services research and health data. From information provided to us by these funders—including AHRQ, National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC)—funding for this field remained relatively constant from FY 2003 - 2008 and did not keep pace with inflation. In stark contrast, spending on health care overall has risen faster than the rate of inflation—from \$1.4 trillion in 2000 to nearly \$2.2 trillion in 2007.<sup>ii</sup> The total federal investment in health services research and data by our estimates approaches \$1.7 billion in FY 2008—representing just 0.074 percent of the \$2.2 trillion dollars we spend on health care annually.<sup>iii</sup>

The Coalition for Health Services Research greatly appreciates the Subcommittee's recent efforts to increase the federal investment in health services research and comparative effectiveness research through the FY 2009 Omnibus Appropriations Act and the American Recovery and Reinvestment Act of 2009. This funding provides a new high watermark for the field and represents the largest single funding increase health services research has experienced. With comprehensive health reform on the horizon, we ask that the Subcommittee continue to strengthen the capacity of the health services research field to address the pressing challenges America faces in providing access to high-quality, cost-effective care for all its citizens.

***Agency for Healthcare Research and Quality***

AHRQ is the lead federal agency charged with supporting unbiased, scientific research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. Steady, incremental increases for AHRQ's Effective Health Care Program in recent years, as well as the \$300 million provided to AHRQ in the American Recovery and Reinvestment Act as a down payment on health reform will help AHRQ generate more comparative effectiveness research and expand the infrastructure needed to increase capacity to produce this evidence. However, funding for AHRQ's broader health services research portfolio on health disparities, health care financing and organization, and access and coverage has languished as funding for AHRQ's base has remained relatively flat. Future investments should bolster these other important research topics to balance the recent investments in comparative effectiveness research. Comparative effectiveness research alone will not solve our health system challenges; the full spectrum of health services research on health care costs, quality, and access will be needed to support broader health reform efforts.

In FY 2009, Congress provided AHRQ \$13 million to reverse a decline in the number of, and funding for, grants that support researcher innovation and career development. AHRQ is using this funding for investigator initiated research grants to rejuvenate the free marketplace of ideas through the agency's new Innovations Research Portfolio. We request that Congress provide additional funding to sustain and expand investigator initiated grants in FY 2010.

The Coalition remains concerned about AHRQ's limited investment in training grants for young researchers, which hit new lows in FY 2009—just 40 awards totaling \$5 million—down from nearly double that amount just two years ago. The Coalition requests that Congress will provide AHRQ more funding in FY 2010 for training grants to ensure the field's capacity to respond to the growing public and private sector demand for health services research.

While targeted funding increases in recent years have moved AHRQ in the right direction, more core funding is needed to help AHRQ fulfill its mission. We join the Friends of AHRQ—a coalition of more than 250 health professional, research, consumer, and employer organizations that support the agency—in recommending a FY 2009 base funding level of at least \$405 million, an increase of \$32 million over the FY 2009 level. This investment will allow AHRQ to restore its critical health care safety, quality, and efficiency initiatives; strengthen the infrastructure of the research field; and reignite innovation and discovery.

***Centers for Disease Control and Prevention***

Housed within CDC, the **National Center for Health Statistics** (NCHS) is the nation's principal health statistics agency, providing critical data on all aspects of our health care system. Thanks to NCHS, we know that too many Americans are overweight and obese, cancer deaths have decreased, average life expectancy has increased, and emergency rooms are over-crowded. We also know how many people are uninsured, how many children are immunized, how many Americans are living with HIV/AIDS, and how many teens give birth.

Despite recent funding increases secured through your leadership, NCHS continues to feel the effects of long-term underinvestment, forcing the agency to eliminate or further postpone the collection of such vital information to the point where key data users now question whether NCHS itself is in good health. Years of flat funding and budget shortfalls forced the elimination



of data collection and quality control efforts, threaten the collection of vital statistics, stymied the adoption of electronic systems, and limited the agency's ability to modernize surveys to reflect changes in demography, geography, and health delivery.

The Coalition joins the Friends of NCHS—a coalition of more than 250 health professional, research, consumer, industry, and employer organizations that support the agency—in recommending a base funding level of \$137.5 million in FY 2010 to ensure uninterrupted collection of vital statistics; restore other important data collection and analysis initiatives; to revise, pretest, and plan data collection activities for future calendar years, and modernize its systems to increase efficiency, interoperability, and security. In addition, we respectfully request that you provide NCHS \$15 million in one-time funding to support the states and territories as they implement the 2003 birth certificates and electronic systems to collect birth data in real-time to facilitate public health monitoring and planning. Future supplemental funding will be required to implement the 2003 death certificates in all states and complete the automation of data collection. The Coalition greatly appreciates that through your leadership early versions of the American Recovery and Reinvestment Act in the House and Senate included \$40 million for this infrastructure development; we were disappointed that it had to be eliminated from the final package.

While significant funding has been provided to improve the public health system's capacity to respond to a terrorist attack or a public health crisis such as pandemic flu, insufficient funding has been provided to support research that evaluates the effectiveness of our preparedness interventions and seeks to improve the delivery of public health services. For example, how cost effective are public health and prevention programs? How can the medical care and public health delivery systems be better linked?

CDC's important **Public Health Research** program and **Prevention Research Centers**—a network of academic health centers that conduct public health research—have been flat funded since FY 2006 at levels of \$31 million and \$29 million, respectively. The Coalition requests at least \$35 million for Public Health Research and at least \$33 million for Prevention Research Centers in FY 2010. The programs seek ways to development, translate, and disseminate research to address obesity, diabetes, and heart disease, healthy aging and youth development, cancer risk, and health disparities.

#### ***Centers for Medicare and Medicaid Services (CMS)***

Steady funding decreases for the Office of Research, Development and Information, together with an increasingly earmarked budget, has hindered CMS' ability to meet its statutory requirements and conduct new research to strengthen our public insurance programs—including Medicare, Medicaid, and SCHIP—which together provide coverage to nearly 100 million Americans and comprise 45 percent of America's total health expenditures.<sup>iv</sup> At a time when these programs pose significant budget challenges for both the federal and state governments, it is critical that we adequately fund research to evaluate these programs' efficiency and effectiveness, and seek ways to manage their projected spending growth.

The Coalition supports increasing CMS's discretionary research and development budget from \$31 in FY 2009 to a base FY 2010 funding level of \$45 million—in addition to funding for programmatic earmarks—as a critical down payment to help CMS recover lost resources and

restore research to evaluate their programs, analyze pay for performance and other tools to update payment methodologies, and to further refine service delivery methods.

***National Institutes of Health (NIH)***

The NIH reported that it spent \$743 million on health services research in FY 2008—roughly 2.9 percent of its entire budget—making it the largest federal sponsor of health services research.<sup>1</sup> For FY 2010, the Coalition recommends a health services research base funding level of at least \$940 million—2.9 percent of the \$32 billion the broader health community is seeking for NIH. We encourage NIH to increase the proportion of their overall funding that goes to health services research from 2.9 to 5 percent to assure that discoveries from clinical trials are effectively translated into health services. We also encourage NIH to foster greater coordination of its health services research investment across its institutes.

In conclusion, the accomplishments of health services research would not be possible without the leadership and support of this Subcommittee. As you know, the best health care decisions are based on relevant data and scientific evidence. At a time when you, your congressional colleagues, and members of the new administration are considering major health reform including ways to get more value for current expenditures, health services research and health data are needed more than ever to yield better information and lead to improved quality, accessibility, and affordability. We urge the Subcommittee to accept our FY 2010 funding recommendations for the federal agencies funding health services research and health data.

If you have questions or comments about this testimony, please contact our Washington representative, Emily Holubowich, at 202.484.1100 or [eholubowich@dc-crd.com](mailto:eholubowich@dc-crd.com).

<sup>i</sup> Lieberman, J.A., et. al. "Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia." *New England Journal of Medicine*, Vol. 353, No. 12, pp.1209-1223 (Sept. 22, 2005). Available on the Web at <http://content.nejm.org/cgi/content/abstract/353/12/1209>

<sup>ii</sup> Hartman, M., et. al. "National Health Spending in 2007: Slower Drug Spending Contributes to Lowest Rate of Overall Growth Since 1998," *Health Affairs*, Vol. 28, No. 1, pp. 246-261 (Jan./Feb. 2009).

<sup>iii</sup> *Federal Funding for Health Services Research*, Coalition for Health Services Research (Feb. 2009). Available on the Web at [www.chsr.org](http://www.chsr.org)

<sup>iv</sup> Catlin, A, et. al. "National Health Spending in 2005: The Slowdown Continues," *Health Affairs*, Vol. 26, No. 1, pp. 142-153 (Jan./Feb. 2007).

<sup>1</sup> Health services research dollars as reported by the NIH Research Portfolio Online Reporting Tool (RePORT). NIH launched its RePORT site early in 2009. Data presented are compiled under a new process, at the request of Congress, with the goal of providing better consistency and transparency in the reporting of its funded research. Due to methodology changes, NIH now believes the annual total for health services research is more accurately estimated at \$743 million in FY 2008 rather than the \$1,022 it had previously reported.

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**Statement of the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) on FY 2010 Funding for the National Institutes of Health submitted for the record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, U.S. House of Representatives**  
**The Honorable David Obey, Chair, May 1, 2009**

**Mr. Chairman and Members of the Subcommittee**, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2010 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 13 professional organizations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

CAHT-BSSR would like to thank the Subcommittee and the Congress for the unparalleled funding increases provided for the NIH in the American Recovery and Reinvestment Act and the FY 2009 omnibus bill. These resources will allow our nation's proven and highly competitive biomedical, behavioral and social science research enterprise to sustain the progress that has been made towards better prevention strategies and new treatments for costly conditions along with improved diagnostics. The next step is to build upon this unmatched investment. It is incumbent that we build upon and maintain the capacity that the resources provided through ARRA will facilitate.

Providing adequate resources in FY 2010 that allows the NIH to keep up with the rising costs of biomedical, behavioral, and social sciences research will help NIH begin to prepare for the era beyond recovery. It is essential that funding in 2011 and beyond allow the agency to resume steady, sustainable growth and allow for fulfilling the President's vision of doubling our investment in basic research. **Accordingly, CAHT-BSSR joins the Ad Hoc Group for Medical Research in urging the Subcommittee to increase NIH's funding in FY 2010 at least seven (7) percent.** This level of funding will provide adequate resources to begin to regain the momentum set in place by the completed campaign to double the nation's investment in the promising research supported and conducted by the NIH.

The **behavioral and social sciences** regularly make important contributions to the well-being of this nation as recently reflected in a congressional exhibition, *National Institutes of Health: Improving the Nation's Health Through Behavioral and Social Sciences Research* (<http://www.cossa.org/caht-bssr/caht-bssr.shtml>). Due in large part to the **behavioral and social science research** sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable

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interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

The grandest challenge we face is understanding the brain, behavior, and society -- from global warming to responding to short term pleasures; from self destructive behavior, such as addiction, to life style factors that determine the quality of life, infant mortality rate and longevity. Nearly 125 million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. Significant factors driving the increase in health care spending in the United States are the aging of the U.S. population, and the rapid rise in chronic diseases, many caused or exacerbated by behavioral factors: for example, obesity, caused by sedentary behavior and poor diet; addictions and resulting health problems caused by tobacco and other drug use.

Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur. NIH supports behavioral and social science research throughout most of its 27 institutes and centers. Numerous reports by the National Academy of Sciences (e.g. *The Aging Mind*, *New Horizons in Health: An Integrative Approach*, and *Health and Behavior*) have presented cutting edge research agendas and made eloquent cases for the applicability of the social and behavioral scientific disciplines to the myriad, complex problems of prevention, treatment and cure of diseases as well as the enhancement of quality of life.

CAHT-BSSR applauds the NIH's recognition that the "scientific challenges in developing an integrated science of behavior change are daunting." We especially commend the **new basic behavioral and social science research "blueprint-like" initiative, Opportunity Network for Basic Behavioral and Social Sciences Research (OppNet), being undertaken by the NIH** to examine the important scientific opportunities that cut across the structure of NIH and designed to look for strategic opportunities to build areas of research where there are gaps and that have the potential to affect the missions of multiple institutes and centers. Likewise, we commend the designation of the **"Science of Behavior Change"** in the third cohort of the Common Fund. We agree with the goals of this Roadmap Pilot to "establish the groundwork for a unified science of behavior change that capitalizes on both the emerging basic science and the progress already made in the design of behavioral interventions in specific disease areas. By focusing basic research on the initiation, personalization, and maintenance of behavior change, and by integrating work across disciplines, this Roadmap effort and subsequent trans-NIH activity could lead to an improved understanding of the underlying principles of behavior change. This should drive a transformative increase in the efficacy, effectiveness, and (cost) efficiency of many behavioral interventions."

**The NIH Office of Behavioral and Social Sciences Research (OBSSR)**, authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995, serves as a convening and coordinating role among the institutes and centers at NIH. In this capacity, OBSSR develops, coordinates, and facilitates social and behavioral science research agenda at NIH; advises the NIH director and directors of the 27 Institutes and Centers; informs NIH and the scientific and lay publics of social and behavioral science research findings and methods; and trains scientists in the social and behavioral sciences. **For FY 2010, CAHT-BSSR supports a budget of \$28.61 million for OBSSR, an**

**increase of \$1.87 million, commensurate with our request for, at a minimum, seven (7) percent increase requested for the NIH.**

To achieve its vision of bringing together the biomedical, behavioral, and social sciences research communities to work towards solving the most pressing health challenges faced by society, OBSSR is expanding its efforts to promote and support social and behavioral science research in four areas: 1) problem-based research; 2) basic science; 3) systems-thinking approaches to population health; and 4) interdisciplinary team science. Given the NIH's focus on gene and environment interaction, new leading edge research examining how social and behavioral factors change or alter the actions of genes to influence health and disease is needed. Focus in this area may require the development of new and innovative tools to measure and analyze behavioral and environmental factors.

OBSSR focuses on cross-cutting behavioral and social research issues (e.g. "Long-term Maintenance of Behavior Change") using its modest budget to seed cross-institute research initiatives. OBSSR has spurred cutting edge research in areas such as measures of community health, including new community-based participatory programs supporting intervention research methods to disease prevention and health promotion in medically underserved areas; socioeconomic status; health literacy; and new methodology development.

The Office is also developing a new initiative, **Community Health Labs**, designed to bring the power of cyberinfrastructure to communities addressing specific health community needs. The Labs will allow for better interface between communities and Academic Health Centers (AHC) and would build on and integrate with established infrastructure at the community level. Because they would be tied into national internet-based networks they could allow communities to learn from each other. These networks have the potential to untie local data on: social, economic, institutional and physical environments; population characteristics; behaviors and health; health services, including medical records; and genetic/genomic and other biological data. In addition, AHCs, Population Health Centers and possibly other HHS-supported Centers could partner with communities to collect and integrate locally relevant data on the many factors that contribute to community populations

In March 2009, the Office held its second annual conference on dissemination and implementation research. The conference was in recognition that translational research does not stop at new drugs and vaccines; it also includes delivering interventions to those who need them most. Additionally, "as a way to improve public health in a battered world, understanding poverty counts as much as knowing how proteins fold." Research on dissemination addresses how information on health promotion and care interventions is created, packaged, transmitted and interpreted. Research on implementation explores how such interventions fit within real-world public health and clinical service systems.

As highlighted by former NIH Director Elias Zerhouni on the occasion of OBSSR's 10<sup>th</sup> anniversary in June 2006: *"the OBSSR has been a tremendous asset to NIH throughout its first ten years . . . we are faced with an enormous and evolving national burden of disease and disability, much of which has roots in personal behavior or socioeconomic influences. The need for behavioral and social research and intervention has never been greater, and its impact has never been clearer. We need but look at recent decreases in rates of cancer, largely due to dramatic decreases in tobacco use. We can point to a remarkable demonstration of the pronounced benefits of diet and exercise –*

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*more effective than drug therapy – in preventing the onset of type 2 diabetes among high-risk individuals. These are but two among many shining examples of the widespread benefits to public health realized through our investment in basic and applied behavioral and social science research, so critical to our understanding of health and disease.”*

The following research cited in the *Achievements of the Social And Behavioral Sciences: Improving Health at Home and Abroad* compiled by the OBSSR further illustrates why behavioral and social sciences research is a critical component in generating scientific knowledge to prevent, treat or cure illnesses or enhance health in a broader context.

**Understanding the Links Between Social and Cultural Factors and Health:** Social scientists have made significant strides in shedding light on the basic social and cultural structures and processes that influence health. Social and cultural factors influence health by affecting exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to, availability of, and quality of health care. Social and cultural factors also play a role in shaping perceptions of and responses to health problems and the impact of poor health on individuals' lives and well-being. In addition, such factors contribute to understanding societal and population processes such as current and changing rates of morbidity, survival, and mortality.

**Reducing Tobacco Use --** The biggest public health success story of the 20<sup>th</sup> century may very well be the reduction in tobacco use and related diseases. Behavioral and social science research has demonstrated successes in preventing youth uptake of smoking as well as in developing powerful behavioral and pharmacological interventions that help smokers quit. As a result, in 2006, overall cancer death rates dropped for the first time in a century, driven largely by the dramatic 50 percent reduction in male smoking from 47 percent in the 1960's to less than 23 percent today. While smoking still kills more women than breast cancer, rates are slowing as women quit and fewer adolescents start. Without this research, 40 million Americans might still be smoking today with about 12 million additional premature deaths and billions of dollars in excess cost.

**Improving Mental Health --** Over the past 30 years, our understanding of the bio-behavioral mechanisms and treatment of mental disorders has advanced dramatically. Effective and cost-effective therapies that combine behavioral and pharmacological treatments are now available for treatment of depression, anxiety disorders, and the abuse of nicotine, alcohol and other drugs.

**Improving Health Literacy:** Health literacy is defined as the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” In order for health care and public health systems to serve individuals and populations more effectively and to reduce health disparities in the population, it is critical to understand the nature of health literacy and its relationship to healthy behaviors, illness prevention and treatment, chronic disease management, health disparities, risk assessment of environmental factors, and health outcomes. Behavioral and social scientists have made great strides in improving knowledge of interventions that can strengthen health literacy and improve the positive health impacts of communications between healthcare and public health professionals.

**Reducing the Health Burden of Poverty:** Discoveries in the behavioral and social sciences can inform life-saving environmental and policy changes. One example is the PROGRESA study

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(Programa Nacional de Educacion, Salud, y Alimentacion), an anti-poverty program begun in 1997 that provides aid to 2.6 million poor Mexican families. This study is comprised of an impressive collaboration across disciplines including biomedical, social/behavioral sciences, economics, epidemiology, and demography. The results have been dramatic, showing that the trajectory of health outcomes associated with poverty may be altered within a generation. The PROGRESA intervention was associated with better growth and lower rates of anemia in low-income, rural infants and children in Mexico. This large-scale, real-world study has demonstrated that antipoverty programs that combine education, health, and nutrition interventions can improve the capacity of families to pull themselves out of poverty and adverse health effects that often ensnare generations.

**Slowing the HIV/AIDS Epidemic --** Although still devastating, HIV/AIDS is no longer the epidemic it once was in the U.S. thanks to research breakthroughs in the biological, behavioral, and social sciences. Mother-to-child-transmission of HIV has fallen dramatically due to the widespread use of new antiretroviral drugs during pregnancy and labor. Socio-behavioral studies of risky behavior have improved our ability to prevent risk through improved screening and adherence to treatment. Large scale educational campaigns have been delivered effectively. Lessons learned are being provided to other countries. The impact of these innovations is dramatic. Previously, 1500 to 1800 babies in the United States were born infected with HIV. Today, fewer than 50 HIV-infected babies are born each year. It is estimated that 16,000-20,000 lives have been saved by preventing mother-to-child transmission of HIV in the U.S. Globally, 280,000 cases of HIV infection in children could be averted each year using this effective psychosocial and drug therapy combination.

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**Increasing Life Expectancy and Quality of Life --** In the last century, life expectancy has extended by an astounding amount—from 47 years in 1900 to 77.5 years in 2003. While medical advances increasingly contribute to living longer and healthier lives, the vast majority of improvements in the quality of life have come from changes in our social, economic, and physical environments.

CAHT-BSSR would be pleased to provide any additional information on these issues. Below is a list of coalition member societies. Again, we thank the Subcommittee for its generous support of the National Institutes of Health and for the opportunity to present our views.

#### CAHT-BSSR

American Educational Research Association	Institute for the Advancement of Social
American Psychological Association	Work Research
American Sociological Association	National Association of Social Workers
Association of Population Centers	Population Association of America
Center for the Advancement of Health	Society for Behavioral Medicine
Consortium of Social Science Associations	Society for Research in Child Development
Council on Social Work Education	The Alan Guttmacher Institute (AGI)

*Coalition for the Advancement of Health Through Behavioral and Social Sciences Research*

**Statement of the Coalition of Northeastern Governors  
to the Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives  
Regarding FY 2010 Appropriations for  
the Low Income Home Energy Assistance Program  
May 1, 2009**

The Coalition of Northeastern Governors (CONEG) is pleased to submit this testimony for the record to the House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding FY2010 appropriations for the Low Income Home Energy Assistance Program (LIHEAP).

The Governors appreciate the Subcommittee's continued support for the LIHEAP program, and we thank you for providing the full authorized amount of \$5.1 billion in FY2009 LIHEAP funding. The Governors recognize the considerable fiscal challenges facing the Subcommittee this year. However, we urge you to maintain the \$5.1 billion level in regular FY2010 LIHEAP block grant funding as well as contingency funds to address unforeseen energy emergencies.

LIHEAP is a vital safety net for millions of vulnerable low-income households – the elderly and disabled living on fixed incomes, the working poor, and families with young children. The highest level of LIHEAP assistance is provided to households with the lowest incomes that pay a high proportion of their income (up to 17 percent) for home energy. A December 2007 study by the Oak Ridge National Laboratory found that, in recent years, the increase in the cost of home energy has far outpaced the rate of inflation and the increase in household income. Even with continued belt-tightening, there is just no room in the budget of these low-income households to pay for increasing energy bills.

The current economic crisis exerts additional pressures on these households, making energy assistance more important now than ever before. In 2007, even before the current recession took hold, 8.7 million residential consumers had their electricity or natural gas service terminated for failing to pay their bills, according to a survey by the National Association of Regulatory Utility Commissioners (December 2008). The same survey found at the end of the 2007-2008 winter heating season, the number of electricity and natural gas residential households with past due accounts had jumped to almost 40 million consumers, and represented nearly \$8.7 billion in past due accounts.

According to the National Energy Assistance Directors' Association, the \$5.1 billion in FY2009 LIHEAP funding makes it possible for states to serve approximately 7.3 million households this year. This record number represents a 25 percent increase over last year and reflects the increased unemployment rate and rise in home energy costs. Yet this is only a small portion of the LIHEAP-eligible households in today's economy.



If the \$5.1 billion level of LIHEAP funding is not sustained in FY2010, states nationwide will be forced to eliminate more than 1.5 million families from the program in order to maintain some of the purchasing power of the LIHEAP grant for the program's poorest families, or to reduce benefit levels overall. States in the Northeast already incorporate various administrative strategies that allow them to deliver maximum program dollars to households in need. These include using uniform application forms to determine program eligibility, establishing a one-stop shopping approach for the delivery of LIHEAP and related programs, sharing administrative costs with other programs, and using mail recertification. Opportunities to further reduce LIHEAP administrative costs are limited, since they are already among the lowest of the human service programs.

In spite of these state efforts to stretch federal and state LIHEAP dollars, the need for the program is far too great. Increased, predictable and timely federal funding is vital for LIHEAP to assist the nation's vulnerable, low-income households faced with exorbitant home energy bills. The CONEG Governors urge the Subcommittee to provide \$5.1 billion in regular block grant funding for LIHEAP in FY2010 as well as contingency funds to address unforeseen energy emergencies. This sustained level of funding will help states to provide meaningful assistance to households in need as millions of low-income citizen's struggle with simply unaffordable home energy bills. LIHEAP can continue to provide a vital safety net protecting these vulnerable households from the potentially deadly heat and cold.



**Commissioned Officers Association  
of the U.S. Public Health Service**

**Gerard M. Farrell  
Captain U.S. Navy (Ret)  
Executive Director**

1 May 2009

The Honorable David R. Obey, Chair  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
Rayburn House Office Building, Room 2358-C  
Washington, D.C. 20515

**Re: DHHS Health and Medical Response (HAMR) Teams**

Dear Chairman Obey:

I write to express once again this Association's strong support for full funding in FY 2010 of the Health and Medical Response (HAMR) Teams proposed by the Department of Health and Human Services.

The HAMR Team proposal could not be more timely. Our country is collectively tracking a rapidly spreading epidemic that seemed to come from nowhere just one week ago today. I can think of no better way to make the case for a highly trained and instantly deployable public health asset than to point to the swine flue scare we are in the middle of right now.

For each of the last three years, the U.S. Department of Health and Human Services has included in its budget request approximately \$30 million to create and train two Health and Medical Response (HAMR) Teams of 105 USPHS officers each. The Department has designated this initiative a top priority and a critically essential element in its overall emergency preparedness and disaster response program. Our Association strongly supports the Department's request.

The HAMR Team proposal was not funded for FY 2007 or 2008. It was not funded in the Omnibus spending bill for FY 2009 that Congress approved in March.

Last October, we met with senior House Appropriations staff. Our goal was to understand and hopefully overcome any concerns on the House side about fully funding the proposed HAMR Teams.

We addressed the view that the proposed HAMR teams would somehow diminish or compete with the all-volunteer National Medical Defense System (NDMS) and its Disaster Medical Assistance Teams (DMATs).

The NDMS DMATs are volunteer teams that, when activated under ESF 8, are organized and paid as

temporary federal employees at the GS-15 pay grade. Their mission is to provide clinical medical care, primarily trauma care. They are outfitted and equipped for two weeks of operations. At the end of two weeks, they disband; team members return to their regular private-sector or state or local public service jobs.

HAMR teams, by contrast, would be full-time federal employees. While their primary mission would be emergency preparedness and crisis response, they would also be tasked with a variety of other critically important public health missions including support to state and local health departments. Their pay grades would generally be below that of a GS-15 (more likely in the O-2 to O-4 range).

Their emergency preparedness and crisis response tasking are already defined in ESF 8 and reaffirmed by Katrina lessons learned. They are not short-duration clinical medicine response teams. Their overarching mission is public health. This means restoring and maintaining disrupted water supplies and sanitation systems. It means preventing the spread of disease, including infectious diseases and food-borne and water-borne diseases. It also includes emergency mental health services and support for patients with chronic diseases. These are missions for which the NDMS is neither staffed nor outfitted.

HAMR Teams would be deployed for the long haul. The USPHS Commissioned Corps had officers deployed to the Gulf Coast for several months after Hurricane Katrina, long after the DMAT volunteers had returned home.

HAMR teams are designed to relieve a significant problem that exists now with the deployment of Corps officers who work throughout the federal government at CDC, FDA, IHS, and other federal agencies. The HAMR teams would replace the USPHS Commissioned Corps Rapid Deployment Force (RDF) teams as full-time rather than part-time federal first responders. RDF teams are composed of officers pulled from all the federal operating divisions and agencies. In the aftermath of 9/11 and the hurricane and other natural disasters that have occurred since, the tasking for these teams has increased exponentially. RDF teams have responded to California wildfires; Midwest floods, and a rash of suicides on an Indian reservation, among other emergencies.

This rapid increase in crisis response has exacerbated problems in the federal health agencies where USPHS officers are assigned. The more these RDF team members are called away for ESF 8 missions, the less time they have to devote to their primary jobs – all of them in key public health assignments throughout the federal government.

We sought to allay concerns that HAMR team members would be needlessly and expensively transported from coast to coast for specialized training. While reasonable support for reasonable travel will in fact be necessary, there are certainly no plans (and no reasons) to, say, assign a team to the West Coast but provide the near-continuous training that is required only on the East Coast. (At present, there is little funding for emergency preparedness training of any kind, and we have heard anecdotal accounts of dedicated USPHS officers paying for their training themselves.)

Finally, we addressed the objection that the HAMR team concept is preliminary in nature and has not been adequately thought through. This may possibly reflect a lack of sufficient detail or clarity in DHHS budget documents, but the HAMR Team concept has indeed been carefully thought-through.

We hope to continue this dialogue with members and staff of the House Appropriations Committee's

Subcommittee on Labor, Education, and Health and Human Services. We also want to suggest that Subcommittee staff request a face-to-face meeting with the senior USPHS Commissioned Corps leaders who developed the HAMR Team concept. COA would be pleased to help facilitate such a meeting. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "G. M. Farrell", followed by a horizontal line.

Gerard M. Farrell  
Captain, U.S. Navy (Ret.)  
Executive Director

Angela L. Sharpe, Consortium of Social Science Associations, (202) 842-3525 (alsharpe@cosssa.org)  
**Statement of the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) on FY 2010 Funding for the National Institutes of Health submitted for the record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, U.S. House of Representatives**  
**The Honorable David Obey, Chair, May 1, 2009**

**Mr. Chairman and Members of the Subcommittee**, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2010 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 13 professional organizations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

CAHT-BSSR would like to thank the Subcommittee and the Congress for the unparalleled funding increases provided for the NIH in the American Recovery and Reinvestment Act and the FY 2009 omnibus bill. These resources will allow our nation's proven and highly competitive biomedical, behavioral and social science research enterprise to sustain the progress that has been made towards better prevention strategies and new treatments for costly conditions along with improved diagnostics. The next step is to build upon this unmatched investment. It is incumbent that we build upon and maintain the capacity that the resources provided through ARRA will facilitate.

Providing adequate resources in FY 2010 that allows the NIH to keep up with the rising costs of biomedical, behavioral, and social sciences research will help NIH begin to prepare for the era beyond recovery. It is essential that funding in 2011 and beyond allow the agency to resume steady, sustainable growth and allow for fulfilling the President's vision of doubling our investment in basic research. **Accordingly, CAHT-BSSR joins the Ad Hoc Group for Medical Research in urging the Subcommittee to increase NIH's funding in FY 2010 at least seven (7) percent.** This level of funding will provide adequate resources to begin to regain the momentum set in place by the completed campaign to double the nation's investment in the promising research supported and conducted by the NIH.

The **behavioral and social sciences** regularly make important contributions to the well-being of this nation as recently reflected in a congressional exhibition, *National Institutes of Health: Improving the Nation's Health Through Behavioral and Social Sciences Research* (<http://www.cosssa.org/caht-bssr/caht-bssr.shtml>). Due in large part to the **behavioral and social science research** sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable

interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

The grandest challenge we face is understanding the brain, behavior, and society -- from global warming to responding to short term pleasures; from self destructive behavior, such as addiction, to life style factors that determine the quality of life, infant mortality rate and longevity. Nearly 125 million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. Significant factors driving the increase in health care spending in the United States are the aging of the U.S. population, and the rapid rise in chronic diseases, many caused or exacerbated by behavioral factors: for example, obesity, caused by sedentary behavior and poor diet; addictions and resulting health problems caused by tobacco and other drug use.

Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur. NIH supports behavioral and social science research throughout most of its 27 institutes and centers. Numerous reports by the National Academy of Sciences (e.g. *The Aging Mind*, *New Horizons in Health: An Integrative Approach*, and *Health and Behavior*) have presented cutting edge research agendas and made eloquent cases for the applicability of the social and behavioral scientific disciplines to the myriad, complex problems of prevention, treatment and cure of diseases as well as the enhancement of quality of life.

CAHT-BSSR applauds the NIH's recognition that the "scientific challenges in developing an integrated science of behavior change are daunting." We especially commend the **new basic behavioral and social science research "blueprint-like" initiative, Opportunity Network for Basic Behavioral and Social Sciences Research (OppNet), being undertaken by the NIH** to examine the important scientific opportunities that cut across the structure of NIH and designed to look for strategic opportunities to build areas of research where there are gaps and that have the potential to affect the missions of multiple institutes and centers. Likewise, we commend the designation of the **"Science of Behavior Change"** in the third cohort of the Common Fund. We agree with the goals of this Roadmap Pilot to "establish the groundwork for a unified science of behavior change that capitalizes on both the emerging basic science and the progress already made in the design of behavioral interventions in specific disease areas. By focusing basic research on the initiation, personalization, and maintenance of behavior change, and by integrating work across disciplines, this Roadmap effort and subsequent trans-NIH activity could lead to an improved understanding of the underlying principles of behavior change. This should drive a transformative increase in the efficacy, effectiveness, and (cost) efficiency of many behavioral interventions."

**The NIH Office of Behavioral and Social Sciences Research (OBSSR)**, authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995, serves as a convening and coordinating role among the institutes and centers at NIH. In this capacity, OBSSR develops, coordinates, and facilitates social and behavioral science research agenda at NIH; advises the NIH director and directors of the 27 Institutes and Centers; informs NIH and the scientific and lay publics of social and behavioral science research findings and methods; and trains scientists in the social and behavioral sciences. **For FY 2010, CAHT-BSSR supports a budget of \$28.61 million for OBSSR, an**

**increase of \$1.87 million, commensurate with our request for, at a minimum, seven (7) percent increase requested for the NIH.**

To achieve its vision of bringing together the biomedical, behavioral, and social sciences research communities to work towards solving the most pressing health challenges faced by society, OBSSR is expanding its efforts to promote and support social and behavioral science research in four areas: 1) problem-based research; 2) basic science; 3) systems-thinking approaches to population health; and 4) interdisciplinary team science. Given the NIH's focus on gene and environment interaction, new leading edge research examining how social and behavioral factors change or alter the actions of genes to influence health and disease is needed. Focus in this area may require the development of new and innovative tools to measure and analyze behavioral and environmental factors.

OBSSR focuses on cross-cutting behavioral and social research issues (e.g. "Long-term Maintenance of Behavior Change") using its modest budget to seed cross-institute research initiatives. OBSSR has spurred cutting edge research in areas such as measures of community health, including new community-based participatory programs supporting intervention research methods to disease prevention and health promotion in medically underserved areas; socioeconomic status; health literacy; and new methodology development.

The Office is also developing a new initiative, **Community Health Labs**, designed to bring the power of cyberinfrastructure to communities addressing specific health community needs. The Labs will allow for better interface between communities and Academic Health Centers (AHC) and would build on and integrate with established infrastructure at the community level. Because they would be tied into national internet-based networks they could allow communities to learn from each other. These networks have the potential to untie local data on: social, economic, institutional and physical environments; population characteristics; behaviors and health; health services, including medical records; and genetic/genomic and other biological data. In addition, AHCs, Population Health Centers and possibly other HHS-supported Centers could partner with communities to collect and integrate locally relevant data on the many factors that contribute to community populations

In March 2009, the Office held its second annual conference on dissemination and implementation research. The conference was in recognition that translational research does not stop at new drugs and vaccines; it also includes delivering interventions to those who need them most. Additionally, "as a way to improve public health in a battered world, understanding poverty counts as much as knowing how proteins fold." Research on dissemination addresses how information on health promotion and care interventions is created, packaged, transmitted and interpreted. Research on implementation explores how such interventions fit within real-world public health and clinical service systems.

As highlighted by former NIH Director Elias Zerhouni on the occasion of OBSSR's 10<sup>th</sup> anniversary in June 2006: *"the OBSSR has been a tremendous asset to NIH throughout its first ten years . . . we are faced with an enormous and evolving national burden of disease and disability, much of which has roots in personal behavior or socioeconomic influences. The need for behavioral and social research and intervention has never been greater, and its impact has never been clearer. We need but look at recent decreases in rates of cancer, largely due to dramatic decreases in tobacco use. We can point to a remarkable demonstration of the pronounced benefits of diet and exercise –*

*Coalition for the Advancement of Health Through Behavioral and Social Sciences Research*

*more effective than drug therapy – in preventing the onset of type 2 diabetes among high-risk individuals. These are but two among many shining examples of the widespread benefits to public health realized through our investment in basic and applied behavioral and social science research, so critical to our understanding of health and disease.”*

The following research cited in the *Achievements of the Social And Behavioral Sciences: Improving Health at Home and Abroad* compiled by the OBSSR further illustrates why behavioral and social sciences research is a critical component in generating scientific knowledge to prevent, treat or cure illnesses or enhance health in a broader context.

**Understanding the Links Between Social and Cultural Factors and Health:** Social scientists have made significant strides in shedding light on the basic social and cultural structures and processes that influence health. Social and cultural factors influence health by affecting exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to, availability of, and quality of health care. Social and cultural factors also play a role in shaping perceptions of and responses to health problems and the impact of poor health on individuals' lives and well-being. In addition, such factors contribute to understanding societal and population processes such as current and changing rates of morbidity, survival, and mortality.

**Reducing Tobacco Use --** The biggest public health success story of the 20<sup>th</sup> century may very well be the reduction in tobacco use and related diseases. Behavioral and social science research has demonstrated successes in preventing youth uptake of smoking as well as in developing powerful behavioral and pharmacological interventions that help smokers quit. As a result, in 2006, overall cancer death rates dropped for the first time in a century, driven largely by the dramatic 50 percent reduction in male smoking from 47 percent in the 1960's to less than 23 percent today. While smoking still kills more women than breast cancer, rates are slowing as women quit and fewer adolescents start. Without this research, 40 million Americans might still be smoking today with about 12 million additional premature deaths and billions of dollars in excess cost.

**Improving Mental Health --** Over the past 30 years, our understanding of the bio-behavioral mechanisms and treatment of mental disorders has advanced dramatically. Effective and cost-effective therapies that combine behavioral and pharmacological treatments are now available for treatment of depression, anxiety disorders, and the abuse of nicotine, alcohol and other drugs.

**Improving Health Literacy:** Health literacy is defined as the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” In order for health care and public health systems to serve individuals and populations more effectively and to reduce health disparities in the population, it is critical to understand the nature of health literacy and its relationship to healthy behaviors, illness prevention and treatment, chronic disease management, health disparities, risk assessment of environmental factors, and health outcomes. Behavioral and social scientists have made great strides in improving knowledge of interventions that can strengthen health literacy and improve the positive health impacts of communications between healthcare and public health professionals.

**Reducing the Health Burden of Poverty:** Discoveries in the behavioral and social sciences can inform life-saving environmental and policy changes. One example is the PROGRESA study

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(Programa Nacional de Educacion, Salud, y Alimentacion), an anti-poverty program begun in 1997 that provides aid to 2.6 million poor Mexican families. This study is comprised of an impressive collaboration across disciplines including biomedical, social/behavioral sciences, economics, epidemiology, and demography. The results have been dramatic, showing that the trajectory of health outcomes associated with poverty may be altered within a generation. The PROGRESA intervention was associated with better growth and lower rates of anemia in low-income, rural infants and children in Mexico. This large-scale, real-world study has demonstrated that antipoverty programs that combine education, health, and nutrition interventions can improve the capacity of families to pull themselves out of poverty and adverse health effects that often ensnare generations.

**Slowing the HIV/AIDS Epidemic --** Although still devastating, HIV/AIDS is no longer the epidemic it once was in the U.S. thanks to research breakthroughs in the biological, behavioral, and social sciences. Mother-to-child-transmission of HIV has fallen dramatically due to the widespread use of new antiretroviral drugs during pregnancy and labor. Socio-behavioral studies of risky behavior have improved our ability to prevent risk through improved screening and adherence to treatment. Large scale educational campaigns have been delivered effectively. Lessons learned are being provided to other countries. The impact of these innovations is dramatic. Previously, 1500 to 1800 babies in the United States were born infected with HIV. Today, fewer than 50 HIV-infected babies are born each year. It is estimated that 16,000-20,000 lives have been saved by preventing mother-to-child transmission of HIV in the U.S. Globally, 280,000 cases of HIV infection in children could be averted each year using this effective psychosocial and drug therapy combination.

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Council on Social Work Education	The Alan Guttmacher Institute (AGI)

*Coalition for the Advancement of Health Through Behavioral and Social Sciences Research*

Statement by Pamela L. Pressley, Associate Director of Public Affairs  
For the Consortium of Social Science Associations (COSSA)

Submitted for the record to the Labor, Health and Human Service, Education and  
Related Agencies Subcommittee, Committee on Appropriations,  
U.S. House of Representatives  
The Honorable David Obey, Chairman  
April 30, 2009

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Mr. Chairman and Members of the Subcommittee, The Consortium of Social Science Associations (COSSA) appreciates and welcomes the opportunity to comment on the FY 2010 appropriations for a number of agencies in the Department of Health and Human Services.

Supported by more than 110 professional associations, scientific societies, universities, research centers and institutes, COSSA is an advocacy group promoting attention to and Federal funding for social and behavioral science research. *(Please see attached membership list).*

It is our hope that as you move forward with your work on the FY 2010 Labor-HHS-Education Appropriations bill that you will consider our recommendations for the following agencies.

**AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)**

The Agency for Healthcare Research and Quality (AHRQ) supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ provides the high quality, unbiased information needed to make educated decisions about our health care. Through this evidence, AHRQ's research helps improve quality, patient safety, and the overall efficiency of our health care system.

COSSA commends the Subcommittee for its ongoing support of AHRQ particularly the \$300 million provided to AHRQ in the American Recovery and Reinvestment Act which will help AHRQ generate more comparative effectiveness research and expand the infrastructure needed to increase our capacity to produce this evidence.

However, funding for AHRQ's broader research portfolio has lingered putting issues such as health disparities, health care financing and organization, and access and coverage at risk. At a time when you, your congressional colleagues, and members of the new administration are considering major health reform, AHRQ's research is needed now more than ever to build the evidence-base needed to help policymakers improve health and health care.

In support of the Friends of AHRQ, a coalition of health professional, research, consumer, and employer organizations dedicated to ensuring the agency's continued vital role in improving our nation's health, COSSA recommends an FY 2010 base funding level of \$405 million, an increase of just \$32 million over the FY 2009 level. This increase will

preserve AHRQ's current initiatives and get the agency on track to a base budget of \$500 million by 2013.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC is the lead Federal agency for promoting health and safety and providing credible health information through strong partnerships, both nationally and internationally. As the command center for our nation's public health defense system against emerging and reemerging infectious diseases, the CDC faces unprecedented challenges and responsibilities, ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic.

CDC serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. From pandemic flu preparedness and prevention activities to West Nile to smallpox to SARS, the Centers for Disease Control and Prevention is the nation's and the world's expert resource and response center, coordinating communications and action and serving as the laboratory reference center.

The recent Swine Flu outbreak serves as a vital reminder of the importance of ensuring that health promotion, protection and disease prevention are given top priority in federal funding. **COSSA applauds the Subcommittee's continued support of the CDC and strongly recommends at least \$8.6 billion for CDC's "core programs" in FY2010. This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).**

Our request reflects the recommendations of the CDC Coalition of which COSSA is a member. The CDC Coalition is made up of more than 100 groups committed to strengthening our nation's prevention and health promotion programs. We strongly believe that the activities and programs supported by CDC are essential to protect the health of the American people.

**The National Center for Health Statistics (NCHS)**, housed within CDC, is the nation's principal health statistics agency that provides critical information to guide actions and policies to improve the health of the American people. NCHS data document the health status of the U.S. population and identify disparities in health status and the use of health care by race/ethnicity, socioeconomic status, region, and other population characteristics. New demands for health information exceed the capacity of our current data systems. At few points in recent history has the need for information been greater.

The health data collected by NCHS are an essential part of the nation's statistical and public health infrastructure. NCHS collects data on chronic disease prevalence, health care disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance to name a few. This data is used heavily by researchers, and other Federal agencies.

Despite recent budget increases, funding levels continue to threaten the collection of vital information. In support of the Friends of NCHS, a coalition of over 200 organizations that wants to ensure the agency's continued vital role in monitoring our nation's health, COSSA

recommends a FY 2010 funding level of at least \$137.5 million for the agency, with bonus funding of \$15 million to support states as they modernize the vital statistics system to put the agency on the path to a base budget of \$175 million by 2013.

#### HEALTH RESOURCES and SERVICES ADMINISTRATION (HRSA)

The Health Resources and Services Administration (HRSA) also known as “The Access Agency,” is a safety net for medically underserved individuals and families, including 86.7 million Americans who were uninsured for some or all of 2007-2008; 50 million Americans who live in neighborhoods where primary health care services are scarce; more than one million people living with HIV/AIDS, and 34 million vulnerable mothers and children, including children with special health care needs.

The agency’s overarching mission is to provide national leadership, program resources and services to improve access to culturally competent, quality health care; eliminate health disparities; and rebuild the public health and health care infrastructure.

**To respond to the continued challenges HRSA face to achieve its mission COSSA recommends a funding level of at least \$8.5 billion for FY 2010.**

This recommendation is in conjunction with that of the Friends of HRSA, a non-profit and non-partisan alliance of more than 140 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. As a member of the HRSA we support its principal goal to ensure that HRSA’s broad health programs have continued support in order to reach the populations presently underserved by the nation’s patchwork of health services.

This support will support HRSA’s HIV/AIDS program to continue to provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide education and training for health professionals treating people with HIV/AIDS; and address the disproportionate impact of HIV/AIDS on women and minorities.

A funding level of at least \$8.5 billion will allow for continued rural health programs that improve access to care for the 60 million Americans who live in rural areas. Rural Health Outreach and Network Development Grants, Rural Health Research Centers and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas.

In conclusion, COSSA acknowledges the Subcommittee’s history of support for these critical programs that promote health, research, and prevent disease. We hope that support will continue in FY 2010.

We again thank you for the opportunity to present our views.

**GOVERNING MEMBERS**

American Association for Public Opinion Research  
 American Economic Association  
 American Educational Research Association  
 American Historical Association  
 American Political Science Association  
 American Psychological Association  
 American Society of Criminology  
 American Sociological Association  
 American Statistical Association  
 Association of American Geographers  
 Association of American Law Schools  
 Law and Society Association  
 Linguistic Society of America  
 Midwest Political Science Association  
 National Communication Association  
 Rural Sociological Society  
 Society for Research in Child Development

**MEMBERSHIP ORGANIZATIONS**

American Agricultural Economics Association  
 American Association for Agricultural Education  
 Association for Asian Studies  
 Association for Public Policy Analysis and Management  
 Association of Research Libraries  
 Council on Social Work Education  
 Eastern Sociological Society  
 International Communication Association  
 Justice Research and Statistics Association  
 Midwest Sociological Society  
 National Association of Social Workers  
 National Council on Family Relations  
 North American Regional Science Council  
 North Central Sociological Association  
 Population Association of America  
 Social Science History Association  
 Society for Behavioral Medicine  
 Society for Research on Adolescence  
 Society for the Psychological Study of Social Issues  
 Society for the Scientific Study of Sexuality  
 Sociologists for Women in Society  
 Southern Political Science Association  
 Southern Sociological Society  
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 George Washington University  
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 University of South Carolina  
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 Institute for the Advancement of Social Work Research  
 Institute for Women's Policy Research  
 National Bureau of Economic Research  
 National Opinion Research Center  
 Population Reference Bureau  
 Social Science Research Council

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## COUNCIL ON SOCIAL WORK EDUCATION

STRENGTHENING THE PROFESSION OF SOCIAL WORK  
*Leadership in Research, Career Advancement, and Education*

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OFFICE OF THE  
 EXECUTIVE DIRECTOR

**Official Written Testimony for Fiscal Year 2010  
 Submitted to the Subcommittee on Labor, Health and Human Services,  
 Education and Related Agencies  
 Committee on Appropriations  
 United States House of Representatives  
 May 1, 2009**

Submitted by  
 Dr. Julia M. Watkins, Executive Director  
 Council on Social Work Education  
 Phone: 703.683.8080  
 E-mail: jwatkins@cswe.org

On behalf of the Council on Social Work Education, I am pleased to offer this written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies for inclusion in the official committee record. I will focus my testimony on two topics: fostering a skilled, sustainable and diverse social work workforce through training and financial support programs at the Department of Health and Human Services and the Department of Education, and growth for behavioral and social science research at the National Institutes of Health.

The Council on Social Work Education (CSWE) is a nonprofit national association representing more than 3,000 individual members as well as 650 graduate and undergraduate programs of professional social work education. Founded in 1952, this partnership of educational and professional institutions, social welfare agencies, and private citizens is recognized by the Council for Higher Education Accreditation (CHEA) as the sole accrediting agency for social work education in the United States. Social work education focuses students on leadership and direct practice roles helping individuals, families, groups, and communities by creating new opportunities that empower people to be productive, contributing members of their communities.

Vulnerable populations from all walks of life—defined here as children and adults with physical or mental disabilities, those living in poverty, trauma victims, aging individuals, returning veterans, individuals under stress or facing coping challenges both temporary and permanent, and segments of society needing assistance to adjust to changing circumstances or overcome injustices—are faced with hurdles which for some cannot be overcome alone. Social workers help vulnerable populations in society be as healthy and productive as possible by working with them to navigate societal and personal challenges. Social workers are employed in schools, hospitals, VA facilities, rehabilitation centers, social service locations, child welfare organizations, assisted living centers, nursing homes, and faith-based organizations.

### **I. Training Opportunities and Debt Load Relief for Social Workers**

Recruitment and retention pose the most significant challenge to the success of the social work profession. This is true across all sectors (public and private), at all levels (from BSW to the doctoral level), and in all fields of practice (child welfare, public health, mental health, geriatrics, veterans, etc.).

The nation needs a workforce that is skilled, diverse and able to keep pace with demand. In 2004, the Bureau of Labor Statistics reported that by 2012 a total of 209,000 social workers will be needed in the fields of child, family, and school social work; medical and public health social work; and mental health and substance abuse social work. In 2006, the Bureau estimated there would be a total of 258,000 job openings for social workers due to growth and net replacement between 2006 and 2016 in the same fields.

While recruitment and retention can be a significant challenge for many professions, especially those dealing with public health and the delivery of social services, the problem is exceptionally widespread for social work. Recruitment into the social work profession faces many obstacles, the most prevalent being low wages. Recruitment and retention of social workers is needed in every sector, from child welfare to veteran rehabilitation and work with the aging population. For example, a 2008 Institute of Medicine report states, "In 1987 the National Institute on Aging predicted a need for 60,000 to 70,000 geriatric social workers by 2020, yet today only about 4 percent of social workers—one-third of the needed number—specialize in geriatrics."

As we look toward reforming the American health care system, we must consider the needs of the workforce that will be responsible for ensuring the health of the population. The below recommendations for Fiscal Year 2010 would help to ensure that we are fostering a sustainable, skilled and diverse workforce that will be able to keep up with the increasing demand.

#### **Department of Health and Human Services**

The various agencies within the Department of Health and Human Services (HHS) provide training and fellowship opportunities for social workers, as well as loan forgiveness programs to help social workers stay in the field. CSWE urges the Committee's support of the following HHS programs; this is not an exhaustive list:

##### **Minority Fellowship Program, Substance Abuse and Mental Health Services**

**Administration (SAMHSA)** – The goal of the SAMHSA Minority Fellowship Program (MFP), which is administered through the Center for Mental Health Services, is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance abuse field. According to SAMHSA, "Minorities make up approximately one fourth of the population, but only about 10 percent of mental health providers are ethnic minorities." CSWE has been a grantee of this critical program for years, administering funds to exceptional minority social work students. Together with a program at the National Institute of Mental Health (below), CSWE has supported over 500 minority fellows since the program's inception, with about two-thirds of those students having gone on to receive their doctoral degrees. *For FY 2010, CSWE urges the Committee to fund the SAMHSA Minority Fellowship Program at \$7.5 million.* This program has suffered from

flat and declining budgets over the last several years. Thankfully, due to Congressional support, it has been restored year after year, despite efforts by the Bush Administration to cancel it. Funding the MFP at \$7.5 million would directly encourage more social workers of minority background to pursue doctoral degrees in mental health and substance abuse and will turnout minority mental health professionals equipped to provide culturally competent, accessible mental health and substance abuse services to diverse populations.

**Institutional Research Training Program in Social Work Program (T32), National Institute of Mental Health (NIMH)** – The National Institute of Mental Health (NIMH) within the National Institutes of Health (NIH) initiated a training program in the 1970s that sought to increase the number of minority doctoral students focusing their research in mental health. Like the SAMHSA program mentioned above, CSWE has ably administered a grant from NIMH for many years, which provides mentored training opportunities to minority social work researchers. The social work profession depends on culturally-competent and culturally-relevant research to assess the circumstances facing vulnerable populations and the needs of those populations to succeed in their circumstances; evaluate the accessibility to and effectiveness of existing social services; and determine best practices for social work educators and practitioners for serving the community. While this program has been successful in enhancing diversity among social workers conducting mental health research and has allowed more underrepresented social work researchers to be brought into the fold as NIH investigators, NIMH recently announced its plan to cancel the program in 2010 and transition the funds to support the traditional, non-diversity-focused T32 training program at NIMH. CSWE is very concerned about the implications of this decision, both on the diversity of researchers at NIMH and what we feel could lead to an absence of social work research at NIMH. *We hope the Committee will encourage NIMH to take the necessary steps to enhance diversity of the NIH/NIMH grant pool and express to NIMH the value and importance of social work research to the study of mental health.*

**Title VII Health Professions Programs, Health Resources and Services Administration (HRSA)** – The Title VII health professions programs at HRSA provide financial support for education and development of the health care workforce. The emphasis of these programs is on improving the quality, diversity and geographic distribution of the health professions workforce, and is currently the only federal program to do so. These programs provide loans, loan guarantees and scholarships to students and grants to institutions of higher education and non-profit organizations to help build and maintain a robust health care workforce. Social work students and practitioners are eligible for Title VII funding. We thank you for recognizing the value of these programs by providing \$200 million in stimulus funding to the Title VII and Title VIII (nursing) programs in the American Recovery and Reinvestment Act of 2009 (P.L. 111-5). *CSWE urges the Committee to provide \$330 million for the Title VII health professions programs for FY 2010.*

**Loan Repayment Program, Indian Health Service (IHS)** – The Loan Repayment Program (LRP) at IHS offers repayment of health professions educational loans in exchange for a commitment to work at an IHS or other Indian health program priority site for a minimum of two years. Social workers are eligible to participate in this program, as defined in Section 4(n) of the Indian Health Care Improvement Act (P.L. 94-437). With appropriate funding,



*J. Watkins, Council on Social Work Education, May 1, 2009*

this program can serve as an effective recruitment tool. However, the program has been grossly underfunded for a number of years. For example, last year IHS denied funding to 231 health care professionals already working in IHS as well as 95 recruits, due to a lack of resources. ***CSWE, a member of the Friends of Indian Health Coalition, urges the Committee to provide an additional \$18.5 million above FY 2009 funding for the IHS Loan Repayment Program for FY 2010 in order to address the critical recruitment needs of the agency.***

#### **Department of Education**

The last few years have seen the creation of a number of loan forgiveness and training programs for which social work would benefit, if adequately funded. CSWE urges the Committee to support the following programs at the Department of Education:

**Graduate Assistance in Areas of National Need (GAANN) Program** – The GAANN program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need for this program; however it was recognized by Congress as an area of national need in the Higher Education Opportunity Act of 2008 as discussed below. We are hopeful that the Department of Education will recognize the importance of including social work in the GAANN program in future years. Inclusion of social work would help to significantly enhance graduate education in social work, which is critically needed in the country's efforts to foster a sustainable health professions workforce. ***CSWE supports a budget of at least \$41 million for GAANN in FY 2009.*** However, if social work were to be added by the Department as a new area of national need, additional resources would need to be provided so as not to take funding away from the already determined areas of national need.

**Loan Forgiveness for Service in Areas of National Need Program** – The Higher Education Opportunity Act of 2008 (P.L. 110-315) created the Loan Forgiveness for Service in Areas of National Need program. This program applies to full-time workers who are employed in areas of national need, such as social workers working in public or private child welfare agencies or mental health professionals with at least a master's degree in social work. ***CSWE urges full funding for this new program for FY 2010.***

In addition to these discretionary programs, a number of mandatory programs were created in the College Cost Reduction Act of 2007 (P.L. 110-84). We look forward to working with the Department of Education as these programs are implemented. Among the programs that include social work education are:

**Income-Based Repayment Program** – The Income-Based Repayment (IBR) program will begin operation in July 2009. This new program caps federal student loan payments at a reasonable percentage of income and cancels most remaining balances of student loans after 25 years. ***CSWE will be monitoring the implementation of this new program to assess the extent to which it is assisting social workers address their debt load reduction needs.***

**Income Contingent Payment for Public Sector Employment Program (Public Service Loan Forgiveness)** – The College Cost Reduction Act of 2007 revised the Income

*J. Watkins, Council on Social Work Education, May 1, 2009*

Contingent Payment for Public Sector Employment program, which previously allowed a borrower who works in public service to pay their loans over 25 years after which their debt would be forgiven. The law now states that public service workers working for an eligible non-profit can cancel their loans after 10 years of service for loans taken out after October 1, 2007. ***Like the IBR program, CSWE plans to monitor the implementation of this new program to assess its success in assisting social workers address high educational debt load.***

## **II. Support for Behavioral and Social Science Research**

Behavioral and social science research, primarily funded out of the National Institutes of Health, has helped us to gain a better understanding of how behavior affects health. Behavioral and social science research allows us to identify and sometimes prevent or mitigate the environmental factors and behavioral influences that play a role in the incidence of disease and conditions like obesity, HIV/AIDS, mental health, cancer, and substance abuse. In addition, behavioral and social science research will become increasingly critical in our efforts to address emerging questions and challenges, such as global climate change and its impacts on people and their behaviors.

The Office of Behavioral and Sciences Research (OBSSR) at NIH is responsible for coordinating the behavioral and social science activities across NIH's 27 institutes and centers, ensuring that the social and behavioral aspects of human health are studied as part of NIH's basic and translational research activities.

CSWE would like to thank the Congress for its generous support for NIH, as exemplified by the passage of the FY 2009 Omnibus Appropriations Bill (P.L. 111-8) and the American Recovery and Reinvestment Act of 2009 (P.L. 111-5). ***In order to continue the momentum started by the doubling of the NIH budget a number of years ago and perpetuated by the funding you provided in the FY 2009 appropriations bill and stimulus act, CSWE urges the Committee to provide at least \$32.4 billion to NIH for FY 2010. In addition, we hope the Committee will urge NIH's institutes and centers to provide commensurate increases for the behavioral and social science activities across the agency.***

As we take on the challenges of health care reform, it will be critical that we invest in the development of the social work profession. Social workers represent the end of the research pipeline, delivering evidence-based practices and therapies from bench to trench. They serve as "implementers" of scientific knowledge, helping vulnerable populations find their voice and achieve access to science and technology. NIH, the nation's premier medical and behavioral research agency, has significant contributions to offer.

Thank you for the opportunity to express these views on behalf of the Council on Social Work Education. We hope the Subcommittee will take these points into consideration as you move forward in the FY 2010 appropriations process. Please do not hesitate to contact me with any questions.



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On behalf of the Cystic Fibrosis Foundation, and the 30,000 people with cystic fibrosis (CF), we are pleased to submit the following testimony regarding fiscal year 2010 appropriations for cystic fibrosis-related research at the National Institutes of Health (NIH) and other agencies.

#### **ABOUT CYSTIC FIBROSIS**

Cystic fibrosis is a life-threatening genetic disease for which there is no cure. People with CF have two copies of a defective gene, known as CFTR, which causes the body to produce abnormally thick, sticky mucus that clogs the lungs and results in fatal lung infections. The thick mucus in those with CF also obstructs the pancreas, making it difficult for patients to absorb nutrients from food.

Since its founding, the Cystic Fibrosis Foundation has maintained its focus on promoting research and improving treatments for CF. More than thirty drugs are now in development to treat CF, some which treat the basic defect of the disease, while others target its symptoms. Through the research leadership of the Cystic Fibrosis Foundation, the life expectancy of individuals with CF has been boosted from less than six years in 1955 to 37 years in 2007. This improvement in the life expectancy for those with CF can be attributed to research advances and to the teams of CF caregivers who offer specialized care. Although life expectancy has improved dramatically, we continue to lose young lives to this disease.

The promise for people with CF is in research. In the past five years, the Cystic Fibrosis Foundation has invested over \$660 million in its medical programs of drug discovery, drug development, research, and care focused on life-sustaining treatments and a cure for CF. A greater investment is necessary, however, to accelerate the pace of discovery and development of CF therapies. This testimony focuses on the investment required to more rapidly and efficiently discover and develop new CF treatments aimed at controlling or curing CF.

#### **SUSTAINING THE FEDERAL INVESTMENT IN BIOMEDICAL RESEARCH**

This Subcommittee and Congress are to be commended for their steadfast support for biomedical research, and their commitment to the National Institutes of Health (NIH), particularly the effort to double the NIH budget between FY1999 and FY2003 as well as the significant investment provided by the American Recovery and Reinvestment Act (ARRA). These increases in funding brought a new era in drug discovery that has benefited all Americans. Congress must adequately fund the NIH so that it can capitalize on scientific advances in order to maintain the momentum that the doubling and the infusion of funds from ARRA generated.

The flat-funding of the NIH since 2003 has decreased purchasing power, limiting the pursuit of critical research. The Cystic Fibrosis Foundation joins the Coalition for Health Funding to recommend increasing the budget for all health discretionary spending by 13 percent in FY2010,

or \$7.4 billion over the FY2009 Omnibus. This increased investment will help maintain the NIH's ability to fund essential biomedical research today that will provide tomorrow's care and cures. If the Committee is not able to recommend funding at this level, Congress should advise the NIH to focus on contributing funds to research partnerships that will accelerate therapeutic development to improve peoples' lives.

#### **STRENGTHENING OUR NATION'S RESEARCH INFRASTRUCTURE**

Because CF is a disease that impacts several systems in the body, several institutes at the NIH share responsibility for CF research. We urge the NIH to pay special attention to advances in treatment methods and mechanisms for translating basic research across institutes into therapies that can benefit patients across institutes. The Cystic Fibrosis Foundation has been recognized for its own research approach that encompasses basic research through Phase III clinical trials, and has created the infrastructure required to accelerate the development of new CF therapies. As a result, we now have a pipeline of more than thirty potential therapies that are being examined to treat people with CF.

#### **The Clinical and Translational Science Awards (CTSA)**

The Clinical and Translational Science Awards (CTSA) program was a key component of the NIH's Roadmap initiative. The program is designed to transform how clinical and translational research is conducted, ultimately enabling researchers to provide new treatments more efficiently to patients. Tremendous effort brought institutions together to rally around this program, yet current funding levels make it difficult for the 39 programs (out of a planned 60) to succeed.

Key to the success of the CTSA is the development of cost-sharing for use of infrastructure services. An example of this mechanism is the General Clinical Research Centers (GCRC), which allowed institutes to reduce their research budgets by having investigators use the GCRC when clinical care such as inpatient stays, lab tests, nursing staff, was made available at no additional cost. Today, individual investigators must provide funds for clinical care cost-sharing from grants funded from other NIH institutes. As research becomes more expensive and private capital dries up, it becomes even more critical to ensure support for translational research, that is, research that moves a potential therapy from development to the market. In order to maximize the potential of the CTSA, multiple institutes within the NIH must be able to provide financial resources for this critical program.

#### **Supporting Clinical Research**

A significant discrepancy persists between the funding awarded to clinical and basic laboratory investigators for first awards. The difference is even greater for second awards and prolonged funding of clinical investigators. The NIH must maintain support for translational research and the investigators piloting those projects. Without this support, the NIH stands to lose an entire generation of clinically trained individuals committed to clinical research. The "generation gap" that would be created by the loss of these clinical researchers would affect the ability of the NIH to conduct world-class clinical investigation and jeopardize the standing of the United States as the world's premiere source for biomedical research.

#### **FACILITATING CLINICAL RESEARCH AND DRUG DEVELOPMENT**

The Cystic Fibrosis Foundation applauds the NIH's efforts to encourage greater efficiency in clinical research. The Foundation has been a leader in creating a clinical trials network to achieve greater efficiency in clinical investigation. Because the CF population is so small, a more significant portion of people with the disease must partake in clinical trials than in most other

diseases. This unique challenge prompted the Foundation to streamline our clinical trials processes. Research conducted by the Foundation is more efficient than ever before and we are a model for other disease groups.

#### **The Model of the Cystic Fibrosis Therapeutics Development Network**

The CF Foundation's established clinical research program, the Therapeutics Development Network (TDN), plays a pivotal role in accelerating the development of new treatments to improve the length and quality of life for cystic fibrosis patients. Lessons learned from its centralization of data management and analysis and data safety monitoring in the TDN will be useful in designing clinical trial networks in other diseases. We urge the Committee to direct the NIH and other agencies to allocate additional funds for innovative therapeutics development models like the TDN. The Cystic Fibrosis Foundation urges the Committee to allocate additional resources for clinical research in order meet the demand for testing the promising new therapies for cystic fibrosis and other diseases.

#### **Alternative Models for Institutional Review Boards**

We are pleased that the Department of Health and Human Services has encouraged the exploration of alternative models of IRBs, including central IRBs, by the CTSA. We encourage Congress to urge the Department to demonstrate more aggressive leadership in persuading all academic institutions to accept review by a central IRB—without insisting on parallel and often duplicative review by their own IRB—at least in the case of multi-institutional trials in rare diseases. Such oversight could help provide greater expertise to improve trial design and enable critical research to move forward in a timelier manner without undermining patient safety.

#### **Research Compensation for Supplemental Security Income**

An additional impediment in our effort to accelerate the development of new therapies is the Social Security Administration's current Supplemental Security Income (SSI) rules, which count research compensation for participation in a clinical drug study as income for determining SSI. This policy creates an unnecessary barrier to clinical trial participation for a significant number of people with CF, and thus severely limits efforts to develop new therapies. We urge the Committee to direct the Social Security Administration to disregard any compensation to an individual who is participating in a clinical trial testing rare disease treatments that has been reviewed and approved by an institutional review board and meets the ethical standards for clinical research for the purposes of determining that individual's eligibility for the SSI program.

#### **Partnership with the National Center for Research Resources (NCRR)**

The CTSA program, administered by the NCRR, encourages novel approaches to clinical and translational research, enhances the utilization of informatics, and strengthens the training of young investigators. The Cystic Fibrosis Foundation has enjoyed a productive relationship with the NCRR to support our vision for improving clinical trials capacity through its early financial support of the TDN. Recently, however, the NCRR decided to reject funding for disease-specific networks in favor of those without a disease focus. As a result of this policy, some of the best clinical research consortia are prohibited from competing for NCRR grants, including but not limited to the CF TDN. We urge the NCRR to reverse this decision.

#### **SUPPORTING DRUG DISCOVERY**

The Cystic Fibrosis Foundation's clinical research is fueled by a vigorous drug discovery effort; early stage translational research of promising strategies to find successful treatments for this

disease. Several research projects at the NIH will expand our knowledge about the disease, and could eventually be the key for controlling or curing cystic fibrosis.

#### **Exploring Protein Misfolding & Mistrafficking**

We applaud the National Heart, Lung and Blood Institute (NHLBI), and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for their initiatives that target research on protein misfolding, and urge an aggressive commitment to facilitate continued exploration in this area to build upon promising discoveries. We urge the NIH to continue to devote special attention to research in protein misfolding and mistrafficking, an area which could yield significant benefits for patients with CF and other diseases where misfolding is an issue.

#### **Opportunities In Animal Models**

The Cystic Fibrosis Foundation is encouraged by the NIH's investment in a research program at the University of Iowa to study the effects of CF in a pig model. The program, funded through research awards from both NHLBI and the Cystic Fibrosis Foundation, bears great promise to help make significant developments in the search for a cure. While a company has been established to produce the animals, the infrastructure and extensive animal husbandry required to keep the animals alive and conduct research on them is available at few academic institutions. We urge additional funding to create a facility that would enable researchers from multiple institutions to conduct research with these models.

#### **Facilitating Scientific Data Connections**

An explosion of data is emerging from "big science" projects such as the Human Genome Project and the International HapMap Project. We encourage investments by NIH into the development of systems that permit the linkage of gene expression, protein expression and protein interaction data from independent laboratories. While construction of such an interface would be difficult, it would undoubtedly facilitate generations of new ideas and open new areas of medically important biology.

#### **Increasing Investment in Inflammatory Response Research**

Cystic fibrosis, like diseases such as inflammatory bowel disease, chronic bronchitis, and rheumatoid arthritis, cause an intense inflammatory response. The Cystic Fibrosis Foundation enthusiastically supports investments by the NIH to gain a greater understanding of inflammatory signaling and inflammatory cascades, which would lead to improved methods of safely interfering with the inflammatory process and contributing to the health and wellbeing of the US population.

#### **Supporting High Throughput Screening**

The committee should urge the NIH to continue to fund high throughput screening initiatives in keeping with the NIH Roadmap suggestions. Support for the follow-up and optimization of compounds identified through this type of screening can help to bridge the development gap and bring about more drugs that can make it to patients' bedsides.

#### **Funding Systems Biology Platforms**

In order to rapidly accelerate the identification of potential biomarkers and understand the mechanisms of action of CFTR function, data generated from multiple laboratories and scientific must be integrated. To address this, the Cystic Fibrosis Foundation has partnered with a systems biology company called GeneGo to generate a cystic fibrosis-focused systems biology platform to illustrate the various effects of CFTR dysfunction in multiple cell systems. The CF

Foundation urges NIH to provide additional funding to support research efforts aimed at leveraging systems biology platforms to integrate multiple disciplines within the CF research community in order to accelerate drug development and biomarker validation for cystic fibrosis.

**Small Business Innovation Research Program at NIH**

Small Business Innovation Research (SBIR) program grants allocated by the NIH have helped many small biotechnology and pharmaceutical companies to develop vital treatments for a variety of diseases. Several companies developing CF treatments have used SBIR grants to fund their development process.

The SBIR program could provide further support by directing that a portion of all grants awarded be used for rare disease research. With such a small portion of the population likely to purchase the drugs, research to produce drugs to treat rare diseases is often considered too large a financial risk to take on. It is important to note, however that there are over 25 million Americans with a rare disease. By directing even small dollar grants to develop drugs for these diseases, Congress can eliminate some of the risk that keeps biotechnology and pharmaceutical companies from developing drugs for rare diseases.

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The NIH has wisely focused on translational research as a touchstone for ensuring the relevance of the agency to the American public. The CF Foundation is the perfect example of this notion, having devoted our own resources to developing treatments through drug discovery, clinical development, and clinical care. Several of the drugs in our pipeline show remarkable promise in clinical trials and we are increasingly hopeful that these discoveries will bring us even closer to a cure. Encouraged by our successes, we believe the experience of the CF Foundation in clinical research can serve as a model of drug discovery and development for research on other orphan diseases and we stand ready to work with NIH and Congressional leaders. On behalf of the Cystic Fibrosis Foundation, we thank the Committee for its consideration.

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The federal government can dramatically reduce the risk and incidence of healthcare-associated infections, at a profit, by following the lead of the 16 US states\* - 32%; nearly 1/3rd of them - that have eliminated, as required by federal law, rules and policies, Medicaid funding of medically unnecessary, elective circumcisions. The Special Statement below - also available at <http://www.doctorsopposingcircumcision.org/DOC/mrsa.html> - explains this in more detail.

Federal funding of other medically unnecessary, elective medical procedures such as medically unnecessary, elective C-sections should also be eliminated, in compliance with federal policy and common sense, both of which require that Medicaid taxes be spent for necessary medicine, not for unnecessary medicine.

The only question that really must be answered here is this one: "If you have only enough money to pay for necessary medicine that is legal to pay for, or for unnecessary medicine that is illegal to pay for, but not for both, which do you choose to buy for your family (or, in this case, for the nation)?"

This may be the easiest decision with which government has ever been confronted. How easy can governing get?

\* - Medicaid no longer covers medically unnecessary, elective circumcisions in Arizona, California, Florida, Idaho, Louisiana, Maine, Minnesota, Mississippi, Missouri, Montana, Nevada, North Carolina, North Dakota, Oregon, Utah, and Washington.

### **Doctors Opposing Circumcision Special Statement**

#### **Epidemic Methicillin-Resistant *Staphylococcus Aureus*: Dramatically Increased Risk for Circumcised Newborn Boys**

Pryles (1958) reported that *Staphylococcus aureus* is a bacterium that has the ability to evolve and develop resistance to antibiotics in wide use.<sup>1</sup> Jevons (1961) confirmed this finding.<sup>2</sup> Curran (1980) reported *S. aureus* produces a tissue-destroying exotoxin.<sup>3</sup> After six decades of antibiotic use, forms of *S. aureus* have evolved that are resistant to most common antibiotics, and this has become an important public health problem.<sup>4</sup> These are given the name "methicillin-resistant *Staphylococcus aureus*" (MRSA). MRSA was once found primarily in hospitals, but new strains have entered the community.<sup>4</sup> These new strains have acquired several new virulence factors.<sup>4</sup> The existence of these virulent antibiotic-resistant pathogens pose serious problems for clinical management of infected patients.<sup>4</sup>



Recent reports indicate that community-associated methicillin-resistant *Staphylococcus aureus* (CA-MRSA) now has reached epidemic proportions in many areas and has become a worldwide problem.<sup>4-12</sup> Kuehnert *et al.* (2006) estimate, based on samples obtained in the National Health and Nutrition Examination Survey, that 32.4 percent of the U.S. population are colonized with *S. aureus*.<sup>13</sup> Circumcision long has been known to increase the risk of *S. aureus* infection in newborn boys. The advent of epidemic CA-MRSA dramatically worsens the risks associated with *Staphylococcus* infection because:

the presence of CA-MRSA in epidemic proportions increases the chance of an infant being infected with MRSA by caregivers.  
 the threat to health is escalated beyond that posed by methicillin-sensitive *Staphylococcus aureus* (MSSA) if an infant should be infected.  
 the risk of death is increased.

This statement reviews the literature regarding MRSA with an emphasis on the risk to newborn circumcised boys.

#### **The Circumcision Wound as Portal-of-Entry for *Staphylococcus aureus***

The circumcision wound is a known portal-of-entry for the pathogen and significantly increases circumcised boys' risk. Sauer (1943) reported fatal *Staphylococcus* broncho-pneumonia after ritual circumcision.<sup>14</sup> Isbester (1959) identified circumcision as a factor in lowering resistance.<sup>15</sup> Thompson *et al.* (1963,1965) reported that boys have about twice the infection rate of girls, and circumcised boys have twice as much SA disease as non-circumcised boys (26 percent compared to 13 percent).<sup>16,17</sup> Kirpatrick & Eitzman (1974) reported a case of staphylococcal septicemia after neonatal circumcision.<sup>18</sup> Annunziato & Goldblum (1978) reported staphylococcal scalded skin syndrome (SSSS) from infected circumcisions.<sup>19</sup> Woodside (1980) reported a case of staphylococcal necrotizing fasciitis after "routine" non-therapeutic circumcision.<sup>20,21</sup> Curran & Al-Salihi (1980) reported that male newborns have 5.5 times as much general exfoliative disease (SSSS) as girls.<sup>3</sup> Enzenauer *et al.* (1985) reported the incidence of *Staphylococcus aureus* (SA) infection on follow-up among the circumcised males to be more than twice as high as among the non-circumcised males and 4 times higher than females.<sup>22</sup> Stranko *et al.* (1986) reported staphylococcal impetigo in newborn circumcised males.<sup>23</sup> Bliss *et al.* (1997) reported two cases of staphylococcal necrotizing fasciitis after circumcision.<sup>24</sup> Boys already are at greater risk of SA infection than girls and neonatal circumcision worsens that disadvantage.<sup>3, 14,17,20-24</sup>

(photos available at  
<http://www.doctorsopposingcircumcision.org/DOC/mrsa.html>)

Initial presentation of post-circumcision  
 staphylococcal necrotizing fasciitis

Patient after surgical debridement of infected tissue

#### **Transmission of Infection**

The strictest aseptic surgical technique may not prevent infection of the circumcision wound with SA because the circumcision wound may be infected while the infant patient is in the newborn nursery or in the community after leaving the hospital. SA spreads rapidly through hospital nurseries and newborn boys quickly become colonized with SA.<sup>13,9,17,22-30</sup> Infection frequently affects the diaper and groin area.<sup>16,22,29</sup> Gooch & Brit (1978) reported that 24 percent of newborns are colonized at time of discharge and, of these, 2 percent have an infection.<sup>29</sup> Enzenauer *et al.* (1984) commented, "Circumcision, by its very nature, requires more staff-person 'hands-on' contact, both during the procedure and during preoperative and postoperative care," so circumcised boys are more likely to be infected.<sup>30</sup> Boys may also become infected in the home environment after leaving the hospital.<sup>28,31</sup>

### Previous Nursery Outbreaks

There are numerous reports of outbreaks of SA among circumcised boys in hospital nurseries. Remington & Klein reported 25 outbreaks from 1961 to 1987 in U.S. hospital nurseries.<sup>32</sup> Zafar *et al.* (1995) reported an outbreak of MRSA in a Virginia nursery.<sup>33</sup> Hoffman *et al.* (2000) reported an outbreak of erythromycin-resistant methicillin sensitive *Staphylococcus aureus* among circumcised boys in a newborn nursery in North Carolina.<sup>34</sup> Rabin (2003) reported an outbreak of MRSA among circumcised boys in the St. Catherine's Hospital nursery on Long Island.<sup>35</sup> Saiman *et al.* (2003) reported the outbreak of MRSA in a New York City newborn nursery.<sup>36</sup> Nabiar *et al.* (2003) reported the outbreak of MRSA in a Washington, DC, newborn intensive care unit with one death.<sup>37</sup> Bratu *et al.* (2005) reported an outbreak of MRSA in the nursery of a New York City hospital and said "the introduction of CA-MRSA strains into neonatal units represents an especially serious challenge."<sup>38</sup>

Bratu *et al.* (2005) identify surgical operations as a risk factor for MRSA infection in the newborn.<sup>38</sup> Other researchers identify male neonatal circumcision as a *specific risk factor*.<sup>39,40</sup> Nguyen *et al.* (2007) report that circumcised newborn boys are twelve times more likely to get a MRSA infection than a non-circumcised boy.<sup>40</sup>

### Manifestations of Infection with MRSA

Some strains of MRSA produce fulminant infection that may progress rapidly to death.<sup>4</sup> Isaacs *et al.* (2004) report that osteomyelitis and/or septic arthritis occurs in connection with MSSA, but more skin infection and cellulitis occurs in connection with MRSA.<sup>9</sup> Zetola *et al.* (2005) report more outbreaks of skin infections, including epidemic furunculosis with possible septic shock, and cases of severe invasive pulmonary infections, including necrotizing pneumonia, in young, otherwise healthy people.<sup>4</sup>

In a paper presented to the American Academy of Pediatrics describing the effects of methicillin-resistant *Staphylococcus aureus* (MRSA) in newborns, Fortunov *et al.* (2005) report heavy outbreaks of pustulosis in the diaper area along with invasive infections including bacteremia, urinary tract infection, musculoskeletal infections, and empyema (pus in a body cavity).<sup>31</sup> Fortunov *et al.* report MRSA in boys peaks at 7-12 days of age, which would be 6-11 days after non-therapeutic neonatal circumcision.<sup>31</sup> The incubation period reported by Fortunov

*et al.*<sup>31</sup> is similar to that reported by Cohen (1992) for post-circumcision urinary tract infections.<sup>41</sup> No peak was observed in girls.<sup>11</sup> Boys had 73 percent of all infections.<sup>31</sup> Ten of 12 invasive infections were in boys.<sup>31</sup>

MRSA is causing new and previously unknown diseases in infants and young children. Kikuchi *et al.* (2003) reported a new disease called *neonatal toxic shock syndrome-like exanthematous disease* (NTED).<sup>40</sup> Adem *et al.* (2005) report three fatal cases of staphylococcal Waterhouse–Friderichsen Syndrome in young girls.<sup>43</sup>

### **Mortality**

*Staphylococcus aureus* infection was often fatal in the pre-antibiotic era.<sup>44</sup> If the SA is methicillin-resistant, mortality increases.<sup>4,5,45,46</sup> and death is a possible outcome of MRSA infection. Pryles (1958) reported nine deaths among 24 infants with staphylococcal pneumonia for a mortality rate of 37.5%.<sup>1</sup> Thompson *et al.* (1963,1965) report a higher mortality rate for males.<sup>16,17</sup> Fortunov *et al.* (2005) report one male infant death.<sup>31</sup> The CDC (1999) reports four pediatric deaths in North Dakota and Minnesota.<sup>45</sup> Isaacs *et al.* (2004) report a mortality rate of 24.6 percent for MRSA-infected newborn babies as compared with 9.9 percent for MSSA-infected babies.<sup>9</sup> Healy *et al.* (2004) report a mortality rate of 38 percent among MRSA infected newborn infants.<sup>46</sup> Vince (2004) reports 800 deaths a year from MRSA in England and Wales.<sup>47</sup> Noskin *et al.* (2005) report 12,000 inpatient deaths a year in U.S. hospitals caused by MRSA.<sup>50</sup> According to Noskin *et al.*, a patient with MRSA infection is five times more likely to die in hospital.<sup>50</sup> Templeton (2005) reported that, at Great St. Ormond Street Hospital in England, out of 20 children with MRSA infection aged three-years or younger, four died, including one boy, born healthy, who died from MRSA infection 36 hours after birth,<sup>51</sup> for a mortality rate of 20 percent.

### **Costs**

Noskin *et al.* (2005), using data from the National Inpatient Survey, reports that the hospital stay and costs for adult patients triple when the patient has a MRSA infection.<sup>50</sup> No data are available for infant or child patients.

### **Epidemiology**

MRSA infection is an emerging epidemic disease. MRSA infection is not a reportable disease, consequently, epidemiological data have not been collected.

### **Outmoded Medical Society Statements.**

Circumcision policy statements by medical societies do not consider the impact of epidemic MRSA, so their recommendations are no longer appropriate.<sup>52-56</sup> In fact, the American Academy of Pediatrics has issued no statement to its members on the treatment of MRSA.

Even though a recent cost-utility study did not consider the advent of MRSA, it still found non-circumcision to be the better choice for optimum health and well-being.<sup>57</sup> Non-circumcision was the preferred medical choice prior to the arrival of MRSA in epidemic proportions,<sup>52 56 57</sup> and is even more so today. The advent of MRSA in epidemic proportions increases risks associated with male neonatal circumcision beyond those previously contemplated and further increases the desirability of the non-circumcision option.

MRSA and other antibiotic-resistant varieties of SA, such as vancomycin-resistant *Staphylococcus aureus* (VRSA), increase risk, including death, to newborn circumcised boys.<sup>431 43,44</sup> In view of this increased risk, the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists should terminate their policy, most recently affirmed in 2002,<sup>58</sup> of offering elective medically-unnecessary non-therapeutic neonatal circumcision at parental request.

#### **Management of MRSA infection**

Bliss *et al.* (1997) recommend early diagnosis, followed by rapid and aggressive treatment for a successful outcome.<sup>24</sup> Professors Bamberger & Boyd (2005) provide a recent guidance on treatment.<sup>59</sup> Kaplan (2005) also discusses treatment options.<sup>60</sup> Mortality remains high even with the best treatment.<sup>59</sup>

#### **Action Required**

Doctors Opposing Circumcision consistently has advised parents that genital integrity (non-circumcision) is most likely to produce the highest state of health and well-being<sup>56,57</sup> and is the preferred medical option for newborn boys.<sup>61</sup> The arrival of community MRSA in epidemic proportions adds additional force to that recommendation.

Public health officials should act to suspend the performance of medically-unnecessary non-therapeutic circumcision of boys.

Hospital administrators must respond to this new threat to all newborn infants and especially circumcised male infants by limiting circumcisions to those for which there is a clear and present immediate medical indication and by increasing aseptic protocols in newborn nurseries.

Medical practitioners must consider the epidemic status of MRSA and exercise their independent judgment regarding the performance of non-therapeutic neonatal circumcision. There is an ethical duty to decline and avoid scientifically invalid treatment, especially when it puts the patient at risk.<sup>60</sup> Doctors must act in the best interests of their child-patients regardless of parental requests.<sup>63-65</sup> Doctors may conscientiously object to the performance of non-therapeutic circumcision of children.<sup>64-66</sup>

**References:**

Available at <http://www.doctorsopposingcircumcision.org/DOC/mrsa.html>

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**REGARDING FISCAL YEAR 2010 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTES OF HEALTH AND THE  
NATIONAL INSTITUTE OF  
NEUROLOGICAL DISORDERS AND STROKE.**

**SUBMITTED TO THE  
HOUSE COMMITTEE ON APPROPRIATIONS; SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND  
RELATED AGENCIES**

**MAY 1, 2009**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2010:**

- **PROVIDE A FUNDING INCREASE OF AT LEAST 7% FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND ITS INSTITUTES AND CENTERS.**
- **URGE THE NATIONAL INSTITUTE ON NEUROLOGICAL DISORDERS AND SROKE (NINDS), THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD), AND THE NATIONAL EYE INSTITUTE (NEI) TO EXPAND THEIR RESEARCH PORTFOLIOS ON DYSTONIA.**
- **URGE THE NIH OFFICE OF RARE DISEASES (ORD) TO EXPLORE OPPORTUNITIES TO PARTNER WITH THE DYSTONIA MEDICAL RESEARCH FOUNDATION (DRMF) AND ADVANCE DYSTONIA RESEARCH.**

Dystonia is a neurological movement disorder characterized by powerful and painful involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. There are several different variations of dystonia, including; focal dystonias, which affect specific parts of the body, and generalized dystonia, which affect many parts of the body at the same time. Some forms of dystonia are genetic and others are caused by injury or illness. Dystonia does not affect a person's consciousness or intellect, but is chronic and progressive. In North America alone, conservative estimates indicate that between 300,000 and 500,000 individuals suffer with dystonia. Currently, there is no known cure and treatment options remain limited.

While the underlying mechanisms of dystonia remain a mystery and the onset of symptoms can occur for a number of reasons, two therapies have emerged with proven health benefits to the dystonia patient community. Botulinum toxin injections and deep brain stimulation have shown varying degrees of success, depending on the individual, in alleviating a dystonia patient's symptoms. More research is needed to fully understand how to combat and cure dystonia, and in the mean time, maintaining patient access to life-improving therapies remains critical.

#### **DEEP BRAIN STIMULATIONS (DBS)**

Deep brain stimulation (DBS) is a surgical procedure that was originally developed to treat Parkinson's disease, but is now being applied to severe cases of dystonia. A neurostimulator, or brain pacemaker, is surgically implanted and delivers electrical stimulation to the areas of the brain that control movement. While the exact reasons for effectiveness are unknown, the electrical stimulation blocks abnormal nerve signals that cause abnormal muscle spasms and contractions.

Since DBS was approved for use by dystonia patients in 2003, it has drastically improved the lives of many individuals. Results have ranged from quickly regaining the ability to walk and speak, to regaining complete control over one's body and returning to an independent life as an able-bodied person. DBS is currently used to treat severe cases of generalized dystonia, but its promising role in treating focal dystonias is being explored and requires continuous support. Surgical interventions are a crucial and active area of dystonia research and may continue to lead to the development of promising treatment options.

#### **BOTULINUM TOXIN INJECTIONS (BOTOX/MYOBLLOC)**

The introduction of botulinum toxin as a therapeutic tool in the late 1980s revolutionized the treatment of dystonia by offering a new, localized method to significantly relieve symptoms for many people. Botulinum toxin, a biological product, is injected into specific muscles where it acts to relax the muscles and reduce excessive muscle contractions.

Botulinum toxin is derived from the bacterium *Clostridium botulinum*. It is a nerve "blocker" that binds to the nerves that lead to the muscle and prevents the release of acetylcholine, a neurotransmitter that activates muscle contractions. If the message is blocked, muscle spasms are significantly reduced or eliminated.

Injections of botulinum toxin should only be performed by a physician who is trained to administer this treatment. The physician needs to know the clinical features and study the involuntary movements of the person being treated. The physician doing the treatment may palpate (touch) the muscles carefully, trying to ascertain which muscles are over-contracting and which muscles may be compensating. In some instances, such as in the treatment of laryngeal dystonia, a team approach including other specialists may be required.

For selected areas of the body, and particularly when injecting muscles that are difficult or impossible to palpate, guidance using an electromyograph (EMG) may be necessary. For instance, when injecting the deep muscles of the jaw, neck, or vocal cords, an EMG-guided injection may improve precision since these muscles cannot be readily palpated. An EMG measures and records muscle activity and may help the physician locate overactive muscles.

Injections into the overactive muscle are done with a small needle, with one to three injections per muscle. Discomfort at the site of injections is usually temporary, and a local anesthetic is sometimes used to minimize any discomfort associated with the injection. Many dystonia patients frequently rely on botulinum toxins injections to maintain their improved standard of living due to the fact that the benefits of the treatment peak in approximately four weeks and lasts just three or four months. Currently, FDA approved forms of botulinum toxin include Botox and Myobloc.

#### **DYSTONIA AND THE NATIONAL INSTITUTES OF HEALTH (NIH)**

Currently, three Institutes at NIH conduct medical research into dystonia. They are NINDS, NIDCD, and NEI.

NINDS has released important Program Announcements in recent years to study the causes and mechanisms of dystonia. These awards cover a wide range of research areas, which included gene discovery, the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies inherited forms of dystonia, epidemiology studies, and brain imaging. DMRF often works with NINDS to support as much critical research as possible and advance understating of dystonia.

NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia. Spasmodic dysphonia is a form of focal dystonia, and involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. Our understanding of spasmodic dysphonia has been greatly enhanced by research initiatives at NIDCD, like the brainstem systems studies.

NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids from an unknown cause that is associated with abnormal function of the basal ganglion. The condition can progress to the point where facial spasms develop. Presently, NEI is conducting a study entitled, *Mexiletine for the Treatment of Focal Dystonia* and a Doxil® Blepharospasm Treatment Trial, both of which have the potential to significantly improve treatment options for blepharospasm patients.



An emerging area of NIH that has the potential to stimulate important, new research into dystonia is ORD housed in the Office of the Director. ORD can facilitate research networks into certain rare conditions by pulling together resources housed at other NIH Institutes and Centers. Given the prevalence of dystonia, the DMRF would like to work more closely with ORD to stimulate and support new research opportunities.

DMRF also supports many extramural researchers studying dystonia. Research includes: exploring improved clinical rating scales for dystonia, elevations of sensory motor training, utilizing Botox as a possible treatment for focal hand dystonia, characterization of abnormalities in sensory regions of the brain, treatments for spasmodic dysphonia, deep brain stimulation (the direct electrical stimulation of specific brain targets), non-invasive transcranial brain stimulation, anatomy imaging of the effect of dystonia on brain activity, and exploring the link between laryngitis and spasmodic dysphonia.

Recent years of near level-funding at NIH have negatively impacted the mission of its Institutes and Centers. For this reason, DMRF applauds initiatives like Senator Arlen Specter's (D-PA) successful effort to provide NIH with \$10.4 billion in stimulus funds. IFFGD urges this Subcommittee to show strong leadership in pursuing substantial funding increase through the regular appropriations process in FY 2010.

*For FY 2010, DMRF recommends a funding increase of at least 7% for NIH and its Institutes and Centers.*

*For FY 2010, DMRF recommends that the National Institute on Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders, and the National Eye Institute be urged to increase their research activities regarding dystonia and partner with voluntary health organizations to promote dystonia research and awareness.*

*For FY 2010, DMRF asks the Subcommittee to urge ORD to consider ways it can partner with DMRF and support dystonia research.*

#### **THE DYSTONIA MEDICAL RESEARCH FOUNDATION (DMRF)**

The Dystonia Medical Research Foundation was founded over 30 years ago and has been a membership-driven organization since 1993. Since our inception, the goals of DMRF have remained: to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community.

**Testimony of Daniel Paul Perez, President & CEO, FSH Society, Inc.**  
**Telephone: (781) 275-7781, e-mail: [daniel.perez@fshsociety.org](mailto:daniel.perez@fshsociety.org) before the Subcommittee**  
**on Labor, Health and Human Services, Education and Related Agencies on the Subject of**  
**FY2010 Appropriations for National Institutes of Health (NIH)**  
**Research on FSHD (Facioscapulohumeral Muscular Dystrophy)**  
**May 1, 2009**

Mr. Chairman, it is a great pleasure to submit this testimony to you today.

My name is Daniel Paul Perez, of Bedford, Massachusetts, and I am testifying today as President & CEO of the FSH Society, Inc. (facioscapulohumeral muscular dystrophy) and as an individual who has this common and most prevalent form of muscular dystrophy.

**The Need for NIH Funding for FSHD**

My testimony is about the profound and devastating effects of a disease known as facioscapulohumeral muscular dystrophy which is also known as facioscapulohumeral muscular disease, FSH muscular dystrophy or FSHD, and the urgent need for increased NIH funding for research on this disorder. According to our research, only a limited amount of work is going on across all the institutes at the NIH. In fact, only 3 of the 27 institutes at the NIH are funding FSHD research, e.g., the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Arthritis, Musculoskeletal and Skin Disease (NIAMS), and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). Currently, the level of funding from NINDS, NICHD and NIAMS for FSHD research is approximately \$3,093,269 (source: NIH RCDC RePORT database system).

Since 1994, I have submitted testimony before both House and Senate Appropriations Committees' subcommittees on Labor, Health and Human Services and Education and Related Agencies which stated that NIH and Congress with modest investments could help bring about a significant research and scientific opportunity which would benefit hundreds of thousands of people worldwide.

Almost, two decades later, I still re-appear before Congress older, wiser and physically much weaker. Again and again, I am asking the Congress of the United States of America to consider the value and merit in supporting FSHD research and why this area of research has been so recalcitrant to modest increases in funding by the NIH. As President of the FSH Society and as the chief activist for the hundreds of thousands of individuals living with FSHD in the United States and worldwide, I will continue to testify year after year arguing the case of wanting to live life free from disease. Hopefully, U.S. Congress and the U.S. NIH will move decisively and proactively to fund FSHD at significantly higher thresholds before this terrible disease takes my life, the lives of my family members affected, and thousands of friends affected by FSHD.

FSHD is a series of errors. The deletion of a stretch of repetitive repeats in the chromosomal structure of the tip of chromosome 4 is the first error; the gene, RNA transcript, or protein that it causes to be mis-expressed is the second, and this primary error is repeated without end. This primary error is the lowest common denominator of the FSHD community e.g. the lesion in chromosome 4. The people living with and involved with FSHD all their lifetime deal with resolving the copious manifestations of this first error. Our lives are a testament to the fact that from this primary error, more complex errors will arise, and that there is no end to the error leading to complexity, and complexity leading to further progression of this debilitating disease,

constant loss of physical ability and in individuals with a moderate to severe course of disease a certain death.

The race to find the gene is an enormous undertaking which traces backward through this series of errors to the starting point. It is a complex race with high expectations and rewards. It is a race in which intellects and creative minds strive to win despite operating on severely reduced research budgets and economies. It is a race that America could win within the next five to ten years if it does not make the error of oversight, omission or of apathy. America could make significant gains in understanding the mechanism of the FSH neuromuscular disorder by investing in new methods and techniques of research. America should realize that now is the time to stop the cascading series of errors. Now is the time to understand the complexity of the situation and, in turn, respond by funding many new FSHD research programs.

The United States of America should not miss this tremendous opportunity that would allow the current generation of people with FSHD, and the many other disorders caused by the same biological mechanism, and their future generations to live life free from disease. The FSHD community has been caught in this never ending circle of error leading to complexity and complexity leading to constant loss of skeletal muscle and functioning. Time is of the essence here. Lives are in the balance and the race against this disease is ongoing. The FSHD community believes that now is the time to move to action and it demands bold and persistent experimentation.

Today, I am asking Congress to communicate to the Public Health Service and National Institutes of Health the need for research funding on the FSHD disorder at a level of \$10,000,000 annually in FY2010.

#### **Living with FSHD**

The prognosis of FSHD includes both a loss of muscular strength that limits personal and occupational activities, and a total loss of mobility in perhaps twenty percent of the cases. Hearing loss and retinal abnormalities are associated with FSHD.

In fact, I was born to a family that already experienced the extraordinary difficulty of receiving a proper diagnosis for FSHD. In the first few years of my life, I had been diagnosed as having FSHD and a severe hearing loss, which I have come to find out, is part of FSHD.

At 47 years of age, I consider myself a life long survivor of the severe trauma and tension of FSHD, and I do not say this lightly. I have dealt with the continuing, unrelenting and unending loss caused by FSHD from the first second, into the first minute, hour, day, week, over the months, and through the years. Not for a moment is there a reprieve from continual loss of my physical ability; not for a moment is there a time for me to mourn; not for a moment is there relief from the physical and mental pain that is a result of this disease. There is no known treatment and no known cause for this disease.

FSHD has insidiously and systematically deprived me of my childhood, my adolescence, and the full range of choices in life. FSHD affects the way you walk, the way you dress, the way you work, the way you wash, the way you sleep, the way you breathe, the way you relate, the way you parent, the way you love, the way and where you live, the way you drive, and the way people perceive and treat you. I cannot smile; I can no longer hold a baby in my arms; I cannot close my eyes to sleep; I can no longer run or walk on the beach or climb stairs. Every day I am aware of the things that I may not be able to do tomorrow. This is the reality for the twenty-five thousand people living with FSHD in the United States.

The men, women and children who live with the daily consequences of this devastating disease are your friends, neighbors, fellow taxpayers and contributors to the American way of life. With an historical 88% employment rate and an average educational achievement level of 14 years (source: Impairment and Disability Profiles on Neuromuscular Diseases: FacioScapuloHumeral Muscular Dystrophy, Research and Training Center on Neuromuscular Disease, Department of Physical Medicine & Rehabilitation, University of California, Davis and The National Institute on Disability & Rehabilitation Research, 1994), we personally bear our burden of the health care costs and training expenses to prepare for and maintain financial and personal independence.

With quiet dignity, we live our lives as productively as possible with FSHD.

I am here to remind you that FSHD is still taking its toll. As a patient with facioscapulohumeral muscular dystrophy (FSHD), I have experienced the constant loss of function this disease leaves in its wake.

#### **The Most Prevalent Form of Muscular Dystrophy, Markedly Under-funded at NIH**

It is a fact that FSHD is now published in the scientific literature as the most prevalent muscular dystrophy in the world. The incidence of the disease is conservatively estimated to be 1 in 14,285. The prevalence of the disease, those living with the disease ranges to two or three times as many as that number based on our increasing experiences with the disease and more available and accurate genetic diagnostic tests.

The French government research agency, INSERM (Insitut National de la Santé et de la Recherche Medicale) is comparable to the NIH, and it recently published prevalence data for hundreds of diseases in Europe. Notable is the "Orphanet Series" reports covering topics relevant to all rare diseases. The "Prevalence or reported number of published cases listed in alphabetical order of disease" November 2008 - Issue 10 report can be found at internet web site ([http://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence\\_of\\_rare\\_diseases\\_by\\_alphabetical\\_list.pdf](http://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence_of_rare_diseases_by_alphabetical_list.pdf)). This update contains new epidemiological data and modifications to existing data for which new information has been made available. This new information ranks facioscapulohumeral muscular dystrophy (FSHD) as the most prevalent muscular dystrophy followed by Duchenne (DMD) and Becker Muscular dystrophy (BMD) and then in turn myotonic dystrophy (DM). FSHD is historically presented as the third most prevalent muscular dystrophy in the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 and 2008 (the MD-CARE Act). This new data ranks FSHD as the first and most prevalent.

#### **Estimated Prevalence (Cases / 100,000)**

Facioscapulohumeral muscular dystrophy (FSHD)	7 / 100,000
Duchenne (DMD) and Becker Muscular dystrophy (BMD) types	5 / 100,000
Steinert myotonic dystrophy (DM)	4.5 / 100,000

For men, women, and children the major consequence of inheriting the most prevalent form of muscular dystrophy, FSHD, is a lifelong progressive and severe loss of all skeletal muscles. FSHD is a terrible, crippling and life shortening disease. No one is immune, it is genetically and spontaneously (by mutation) transmitted to children and it affects entire family constellations.

#### **NIH Muscular Dystrophy Funding Has Tripled Since the Inception of the MD CARE Act**

U.S. House of Representatives Appropriations Subcommittee on Labor, HHS, Education FY2010 -- Version for the Hearing Record  
Daniel Paul Perez, FSH Society on facioscapulohumeral muscular dystrophy. 01 May 2009.

Between fiscal year 2006 and 2007, NIH overall funding for muscular dystrophy increased from \$39,913,000 to \$47,179,000, an 18 percent increase.

Between fiscal year 2007 and 2008, NIH overall funding for muscular dystrophy decreased as shown in the "Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)" report on the new Research Portfolio Online Reporting Tool (RePORT) from \$58 million to \$56 million, a 3 percent decrease. These figures are from the new "2007/2008 NIH Revised Method" columns. The same RCDC RePORT system report shows \$47 million as the 2007 figure under the "2007 NIH Historical Method" column, a 23 percent increase and restatement when converting to the new system.

Figures from the RCDC RePORT and the NIH Appropriations History for Muscular Dystrophy report historically provided by **NIH/OD Budget Office & NIH OCPL** show that from the inception of the MD CARE Act 2001, funding has nearly tripled from \$21 million to \$56 million for muscular dystrophy.

#### **NIH FSHD Funding has Remained Level Since the Inception of the MD CARE Act**

Between fiscal year 2006 and 2007, NIH funding for FSHD increased from \$1,732,655 to \$4,108,555. In fiscal 2007, FSHD was 8.7% of the total muscular dystrophy funding (\$4.109M / \$47.179M).

Between fiscal year 2007 and 2008, NIH funding for FSHD decreased from \$4,108,555 to \$3 million under the "2007 and 2008 NIH Revised Method." The "2007 NIH Historical Method" was restated to \$3 million. In fiscal 2008 under "NIH Revised Method," FSHD was 5.3% of the total muscular dystrophy funding (\$3M / \$56M). The previous years 2006/2007 figures are revised and restated under "2007 NIH Historical Method" as (\$3M / \$58M) which is 5.1% of the total muscular dystrophy funding. FSHD funding has merely kept its ratio in the NIH funding portfolio and has not grown in the last seven years.

We highly commend the Director of the NIH on the ease of use and the accuracy of the Research Portfolio Online Reporting Tool (RePORT) report "Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)" with respect to reporting projects on facioscapulohumeral muscular dystrophy.

<b>National Institutes of Health (NIH) Appropriations History</b>		
<b>Sources: NIH/OD Budget Office &amp; NIH OCPL (Dollars in millions)</b>		
<b>&amp; NIH RCDC RePORT</b>		
<b>Fiscal Year</b>	<b>FSHD Research Dollars</b>	<b>FSHD % of MD</b>
2002	\$1.3	5%
2003	\$1.5	4%
2004	\$2.2	6%
2005	\$2.0	5%
2006	\$1.7	4%
2007	\$3	5%
2008	\$3	5%

The MD CARE Act 2008 mandates the NIH Director to intensify efforts and research in the muscular dystrophies, including FSHD, across the entire NIH. It should be very concerning that in the last seven years muscular dystrophy has tripled to \$56 million and that FSHD has remained at

five (5) percent of the NIH muscular dystrophy portfolio or \$3 million. Only three of the institutes at the NIH are funding FSHD. OD, NHLBI, NIGMS, NIBIB, NIDCD, NHGRI, NEI, NIA, NCI and NCRR are all aware of the high impact each could have on FSHD. FSHD is certainly still far behind when we look at the breadth of research coverage NIH-wide.

Now, FSHD is published as the most prevalent muscular dystrophy, and given the extraordinary interest of the scientific and clinical communities in its unique disease mechanism, it defies gravity that it still remains the most prevalent and one of the most underfunded dystrophies at the NIH and in the federal research agency system (CDC, DoD and FDA). In 2008, the third most prevalent dystrophy, Duchenne (DMD) and Becker Muscular dystrophy (BMD) type, received \$22 million from NIH. In 2008, the second most prevalent dystrophy myotonic dystrophy (DM), received \$9 million from NIH. In 2008, the most prevalent dystrophy, facioscapulohumeral muscular dystrophy (FSHD), received \$3 million from NIH. It is now time to flip the stack and to make sure that FSHD with its equal burden of disease and highest prevalence gets more funding, stimulus and that NIH program staff initiates request for applications specifically in FSHD. It is crystal clear, if not completely black and white, that the open mechanism program announcement and investigator driven model are not achieving the goal mandated by the MD CARE Acts 2001/2008 and by the NIH Action Plan for the Muscular Dystrophies as submitted to the Congress by the NIH. Efforts of excellent program staff and leadership at NIH, excellent reviewers and study sections, excellent and outstanding researchers working on FSHD and submitting applications to the NIH, and extraordinary efforts of the volunteer health agencies working in this area have not yet enabled FSHD funding to increase at the NIH. It is time for requests, contracts and calls for researcher proposals on FSHD to bootstrap existing FSHD research worldwide.

I am here once again to remind you that FSHD is taking its toll on your citizens. FSHD illustrates the disparity in funding across the muscular dystrophies and recalcitrance in growth over twenty years despite consistent pressure from appropriations language and Appropriations Committee questions, and an authorization from Congress mandating research on FSHD.

#### **Our request to the NIH Appropriations Subcommittee**

We request this year in FY2010, immediate help for those of us coping with and dying from FSHD. We ask NIH to fund research on FSHD at a level of \$10 million in FY2010.

We implore the Appropriations Committee to request that the Director of NIH, the Chairman/Chairwoman, and Executive Secretary of the federal advisory committee Muscular Dystrophy Coordinating Committee mandated by the MD CARE Act 2008, to increase the amount of FSHD research and projects in its portfolios using all available passive and pro-active mechanisms and interagency committees. Given the knowledge base and current opportunity for breakthroughs in treating FSHD it is inequitable that only three of the twelve NIH institutes covering muscular dystrophy have a handful of research grants for FSHD. We request that the Director of the NIH be more proactive in facilitating grant applications (unsolicited and solicited) from new and existing investigators and through new and existing mechanisms, special initiatives, training grants and workshops – to bring knowledge of FSHD to the next level.

Thanks to your efforts and the efforts of your Committee, Mr. Chairman, the Congress, the NIH and the FSH Society are all working to promote progress in facioscapulohumeral muscular dystrophy. Our successes are continuing and your support must continue and increase.

We ask you to fund NIH research on facioscapulohumeral muscular dystrophy (FSHD) at a level of \$10 million in FY2010.

Mr. Chairman, thank you for this opportunity to testify before your committee.

# Family Violence Prevention Fund

[www.endabuse.org](http://www.endabuse.org)

Testimony of Esta Soler, President and Founder of the Family Violence Prevention Fund

House Appropriations Subcommittee on Labor, Health and Human Services and Education

Submitted for the Record

Support Domestic and Sexual Violence Prevention and Intervention Programs for Fiscal Year 2010

May 1, 2009

The Family Violence Prevention Fund (FVPF) works to end violence against women and children around the world, because every person has the right to live free of violence. The FVPF's National Health Resource Center on Domestic Violence provides critical information to thousands of health care providers, institutions, domestic violence service providers, government agencies, researchers and policy makers each year. Its public education campaigns, conducted in partnership with The Advertising Council, have shaped public awareness and changed social norms for 15 years.

## **Strengthening the Healthcare System's Response to Domestic Violence, Dating Violence, Sexual Assault, and Stalking**

Through our work as the National Health Resource Center on Domestic Violence, I know the critical role health care providers can play in preventing and responding to violence against women and children. But it is not simply a moral imperative that we try to reduce violence and abuse in this country; it is an economic necessity that Congress supports prevention and intervention efforts in the health care system. The Centers for Disease Control and Prevention (CDC) classifies violence and abuse as a "substantial public health problem in the United States," noting the long-term impact of violence and abuse has huge implications for health outcomes and costs.

Children who experience childhood trauma, including witnessing incidents of domestic violence, are at a greater risk of having serious adult health problems including tobacco use, substance abuse, cancer, heart disease, depression and a higher risk for unintended pregnancy. Twenty years of CDC research links childhood exposure to violence with chronic health conditions including obesity, asthma, arthritis, and stroke. It is worth noting that victims, particularly of sexual violence, are linked with obesity. A meta-analysis of research on the impact of adult intimate partner violence finds that victims of domestic violence are at increased risk for conditions such as heart disease, stroke, hypertension, cervical cancer, chronic pain including arthritis, neck and pain, and asthma. In addition to injuries, adult intimate partner violence also contributes to a number of mental health problems including depression and PTSD, risky health

behaviors such as smoking, alcohol and substance abuse, and poor reproductive health outcomes such as unintended pregnancy, pregnancy complications, post partum depression, poor infant health outcomes and sexually transmitted infections including HIV. Studies show that women who have experienced domestic violence are 80 percent more likely to have a stroke, 70 percent more likely to have heart disease, 60 percent more likely to have asthma and 70 percent more likely to drink heavily than women who have not experienced intimate partner violence.

When Congress joined together to reauthorize the Violence Against Women Act (VAWA) of 2005 (P.L. 109-162), the law included new provisions to educate and train health care providers and public health professionals on how to safely screen and intervene in cases of domestic and sexual violence. These provisions were added after years of work by medical associations, health professionals, advocates and a National Health Care Standards Campaign on Domestic Violence funded by the U.S. Department of Health and Human Services. These collaborations successfully developed strategies, tools, and policies to identify and help victims in health settings.

We know that most women seek health care services regularly, either for routine, emergency, perinatal or pediatric care. As a result, health care providers are in a unique position to identify and reach out to victims of violence, long before they may seek help from a domestic violence, rape crisis center, law enforcement, or family member. However, fewer than ten percent of primary care physicians routinely screen patients for domestic violence during regular office visits, according to a study published by the *Journal of the American Medical Association*.

A commitment in funding programs that respond to abuse across the lifespan, intervention strategies, and prevention messages would have significant public health benefits and cost savings to the health care system. While we do not know the full cost of violence and abuse to the health care system, previous studies have shown that those who experience abuse access health care 2 to 2.5 times more frequently than those without that history. Research shows that intimate partner violence alone costs a health plan \$19.3 million each year for every 100,000 women between the ages of 18 and 64 enrolled.

Far more important is the cost of violence and abuse over time. Even five years after abuse has ended, health care costs for women with a history of intimate partner violence remain 20 percent higher than those for women with no history of violence. A study by the CDC in 2003 estimated the direct medical costs of *only* injuries and mental health services related to intimate partner violence at \$4.1 billion alone, this does not include any evaluation of costs associated with chronic health issues or reproductive health issues discussed above and known to be highly prevalent among victims of abuse. A recent report by the Academy on Violence and Abuse estimated the actual cost to the health care system of **violence and abuse may be nearly 17 percent of the total health care dollar or \$333 billion in 2008.**

But early identification and treatment of victims can financially benefit the health care system. Initial and unpublished findings from one study found that hospital-based domestic violence interventions may reduce healthcare costs by at least 20%. Preventing abuse or associated health risks and behaviors clearly could have long term implications for decreasing chronic disease and costs. Because of the long-term impact of abuse on a patient's health, I recommend



integrating assessment for current and lifetime exposure and interventions into routine care. Regular, face-to-face screening of women by skilled health care providers markedly increases the identification of victims of intimate partner violence (IPV), as well as those who are at risk for verbal, physical, and sexual abuse. Routine inquiry of all patients, as opposed to indicator-based assessment, increases opportunities for both identification and effective interventions, validates IPV as a central and legitimate health care issue, and enables providers to assist both victims and their children.

When victims or children exposed to IPV are identified early, providers may be able to break the isolation and coordinate with domestic violence (DV) advocates to help patients understand their options, live more safely within the relationship, or safely leave the relationship. Expert opinion suggests that such interventions in adult health settings may lead to reduced morbidity and mortality. Assessment for exposure to lifetime abuse has major implications for primary prevention and early intervention to end the cycle of violence.

Just as the health care system has always played an important role in identifying and preventing other serious public health problems, I believe it can and must play a pivotal role in domestic and sexual violence prevention and intervention. It is clear that by funding these innovative and life-saving health provisions established by Title V in VAWA 2005, we can help save the lives of victims of violence and greatly reduce health care expenses.

**In order to advance necessary and needed health goals, I urge you to provide \$13 million to the Department of Health and Human Services to fully fund the Violence Against Women Act's Health Care Programs for Fiscal Year 2010, and specifically fund the following L/HHS programs accordingly:**

*Training and Education of Health Professionals program at \$3 million* to train health care providers and students in health professional schools how to identify and screen victims of domestic and sexual violence; ensure immediate safety; document their injuries; and refer them to appropriate services;

*Fostering Public Health Responses at \$5 million* to promote public health programs that integrate domestic and sexual violence assessment and intervention into basic care, as well as encourage collaborations between health care providers, public health programs, and domestic and sexual violence programs; and

*Research on Effective Interventions at \$5 million* to support research and evaluation on effective interventions in the health care setting to improve abused women's health and safety and prevent initial victimization.

#### **Protect Non-Abusive Parents and Children**

Another area of concern is the intersection of domestic violence and child abuse, which often occur in the same family. When child welfare agencies work alone in responding to child maltreatment, they may not understand the complexity of the domestic violence situation and

“preemptively” remove the child without offering services to the adult victim. This can have a devastating result for both the child and the non-abusive caretaker.

By supporting agencies in cooperative efforts to provide services to victims – both children and their non-abusive caretakers – it is possible to keep families safe and united during the difficult process of ending abuse.

Approximately 45 percent of female caregivers of children reported for child maltreatment have experienced intimate partner violence in their lifetime and 29 percent in the past year. In a study of families investigated for child maltreatment, 31 percent of female caregivers reported experiencing intimate partner violence in the past year; however child welfare workers only identified this abuse in 12 percent of the families.

**The Solution: Improve Cooperation between Child Welfare and Domestic Violence Advocates**

Building on what was commonly known as the “Greenbook Project” that was a federally funded demonstration grant program, VAWA 2005 authorized a program to create grants for training and collaboration on the intersection between domestic violence and child maltreatment. The intent is to ensure that non-abusive family members receive the services they need to keep their families safe, and community services can deal with both problems simultaneously, allowing for a better use of our limited resources. As the two problems often occur together, dealing with one problem and not the other is at the peril of our children.

**I urge you to fully fund Training and Collaboration on the Intersection Between Domestic Violence and Child Maltreatment Program at \$5 million to help serve families experiencing violence.**

In addition, I ask that you continue to support full funding for the Family Violence Prevention and Services Act (FVPSA), the nation’s only designated federal funding source for domestic violence shelters and services. As leaders committed to both the prevention of intimate partner violence and to the health and safety of victims, I urge you to fund these critical programs.

Testimony of  
**Richard B. Marchase, Ph.D., President**  
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and  
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On

**FY 2010 Appropriations for the National Institutes of Health**

Submitted to the  
**House Committee on Appropriations**  
**Subcommittee on Labor, Health & Human Services, Education and Related Agencies**

**Representative Dave Obey, Chair**  
**Representative Todd Tiahrt, Ranking Member**

May 1, 2009

On behalf of the Federation of American Societies for Experimental Biology (FASEB), I **respectfully request a funding increase of at least seven percent above the FY 2009 baseline level for the National Institutes of Health (NIH) in FY 2010.** This funding level is an important step toward President Obama's campaign pledge to double funding for basic research over ten years and is necessary to maintain both the existing and future scientific infrastructure. We are in a very crucial time for science in the United States. After years of stagnant funding for research, Congress has recently made significant new investments in NIH. The scientists and researchers represented by FASEB are sincerely grateful to Congress for your faith in the research community and your generosity in providing the resources that are essential for progress in science.

As a Federation of 22 professional scientific societies, FASEB represents nearly 90,000 life scientists, making us the largest coalition of biomedical research associations in the nation. FASEB's mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences, including the research funded by NIH, through service to its member societies and collaborative advocacy. FASEB enhances the ability of biomedical and life scientists to improve—through their research—the health, well-being and productivity of all people.

We especially thank and commend Congress for including the extraordinary investment in medical research at NIH that was included as part of in the *American Recovery and Reinvestment Act* (ARRA) [P.L. 111-5] as well as the \$938 million increase in NIH funding in the Omnibus Appropriations Act for FY 2009 [P.L. 111-8]. In particular, we are deeply grateful to the Chairman and this Subcommittee for your long-standing leadership in support of NIH. These are difficult times for our nation and for people all around the globe, but the affirmation of science is the key to a better future is a strategic step forward.

The recent history of the NIH budget has hindered scientific discovery and limited the capacity of a key engine for today's innovation-based economy. The additional funding in the ARRA and the FY 2009 omnibus are critical first steps to returning the NIH to a course for even greater discovery. These investments give patients, their families and researchers renewed hope for the future, and will help ensure the success of America's medical research enterprise and leadership. The funding increases in the ARRA and the FY 2009 omnibus will provide an immediate infusion of funds into the nation's proven and highly competitive medical research enterprise to sustain the pursuit of improved diagnostics, better prevention strategies and new treatments for many devastating and costly diseases as well as support innovative research ideas, state-of-the-art scientific facilities and instrumentation, and the scientists, technicians, laboratory personnel, and administrators necessary to maintain the enterprise. These funds will also be reinvigorating this nation's ability to produce the human and intellectual capital that will continue to drive scientific discovery, transform health, and improve the quality of life for all Americans. Moreover, we see this as the first step in renewing a national commitment to sustained, predictable growth in NIH funding, which we believe is an essential element in restoring and sustaining both national and local economic growth and vitality as well as maintaining this nation's prominence as the world leader in medical research.

As a result of this Subcommittee's prior investment in NIH, we have made critical advances in understanding basic science, saved and improved the lives of millions of Americans and provided doctors with tools to prevent and treat costly and devastating diseases including:

- **Cardiovascular Disease:** New results from multiple studies provided the strongest evidence to date that a simple blood test for high-sensitivity C-reactive protein (hsCRP), whose characterization was funded by NIH, is a useful marker for cardiovascular disease. Furthermore, scientists have discovered that a daily dose of a commonly used statin, rosuvastatin (Crestor), reduced the risk of heart attack, stroke, and death by nearly half (44 percent) in individuals with high levels of hsCRP but with normal or low levels of low density lipoprotein (LDL), the so-called "bad cholesterol." These developments show great promise in helping clinicians better identify and treat individuals at risk for cardiovascular disease – potentially saving millions more lives.
- **Cancer:** For the first time in a decade, incidence rates for all cancers combined are decreasing, driven largely by declines in some of the most common types of cancer, including breast cancer (2.2 percent decline among women) and prostate cancer (4.4 percent decline). Death rates declined for 10 of the top 15 causes of cancer death among both men and women.
- **Alzheimer's:** Researchers isolated a toxic substance that appears to be a key to understanding Alzheimer's disease, suggesting a possible new target for developing drug therapies to combat the irreversible and progressive disorder. In addition, further insights into the early stages of Alzheimer's may answer questions not only about the disease, but also about age-related memory impairments.
- **Type 2 Diabetes:** An international team that included NIH-funded scientists identified six new genetic variants associated with increased risk of type 2 diabetes. By pinpointing

particular pathways involved in diabetes risk, this discovery can empower new approaches to understanding environmental influences and to the development of better, more precisely targeted drugs.

#### **Investment in NIH is Critical to Taking Advantage of Emerging Scientific Opportunities**

Prior investment in NIH has begun to unlock the secrets of the human genome and allowed scientists to gain new insight into how disease works at the most basic levels within our bodies. Scientists are working tirelessly to translate research results into interventions for our most debilitating medical conditions. NIH also serves an invaluable role in communicating research findings to patients and their families, health care providers, and the general public in critical areas such as increasing knowledge about infectious diseases, improving cognitive health, and reducing health disparities.

#### **The Consequences of Stagnant Funding for Research**

The re-emergence of previously eradicated diseases such as mumps, the development of new health threats, a rapidly aging population, and significant increases in longevity lends a sense of urgency to the need to expedite scientific discovery. Yet even as our need to prevent disease becomes greater and the opportunities to succeed become more numerous, our national commitment to medical research has stagnated:

- “Success rates” dropped to an estimated 18 percent in fiscal year 2009. This means that more than 80 percent of the highly qualified, peer-reviewed research proposals go unfunded. With every unfunded idea, we risk missing or delaying critical discoveries leading to therapies for our most debilitating health conditions.
- The competition for funding is coming at a time when both the interest in careers in the science field and the number of newly-trained researchers entering the workforce is increasing. Doctorates in the critical fields of engineering and biological sciences increased 10 percent and 11 percent respectively, in one year.<sup>1</sup>
- The medical schools, teaching hospitals, universities, and research institutes where NIH research takes place are among the largest employers in their respective communities. In fiscal year 2007, NIH grants and contracts created and supported more than 350,000 jobs that generated wages in excess of \$18 billion in the 50 states.<sup>2</sup>

#### **The Importance of Sustained, Predictable Funding for Research**

The research engine needs a predictable, sustained investment in science to maximize our return on investment. The discovery process—while it produces tremendous value—often takes a

<sup>1</sup> Council of Graduate Schools. 2008. *Graduate Enrollment and Degrees: 1997-2007*. [http://www.cgsnet.org/portals/0/pdf/N\\_pr\\_ED2007.pdf](http://www.cgsnet.org/portals/0/pdf/N_pr_ED2007.pdf)

<sup>2</sup> Families USA. 2008. *In your own backyard: How NIH funding helps your state's economy*. <http://www.familiesusa.org/assets/pdfs/global-health/in-your-own-backyard.pdf>

lengthy and unpredictable path. Recent experience has demonstrated how cyclical periods of rapid funding growth followed by periods of stagnation is disruptive to training, to careers, long range projects and ultimately to progress. NIH needs sustainable and predictable budget growth to achieve the full promise of medical research to improve the health and longevity of all Americans. We must ensure that after the stimulus money is spent we do not have to dismantle our newly built capacity and terminate valuable, on-going research.

The FY 2009 omnibus and the ARRA provided \$38.5 billion for NIH to provide over 16,000 new research grants for live-saving research into diseases such as cancer, diabetes and Alzheimer's. Keeping up with the rising cost of medical research in the 2010 appropriations will help NIH begin to prepare for the "post-stimulus" era. In 2011 and beyond we need to make sure that the total funding available to NIH does not decline and that we can resume a steady, sustainable growth that will enable us to complete the President's vision of doubling our investment in basic research. Consistent with the President's proposal, we respectfully urge this Subcommittee to increase funding for NIH in Fiscal Year 2010 by at least 7 percent over the fiscal year 2009 level.

The federal commitment to biomedical research is profoundly transforming medical practice, preventing disease, and creating better therapies but additional resources are needed to pursue the historic level of scientific opportunity that is available today. We recognize this subcommittee has the especially difficult task of providing funding for a wide range of critical human service programs and thank you for recognizing that prosperity and quality of life are increasingly shaped by investments in science and technology.

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*5,000 Police Chiefs, Sheriffs,  
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Leaders, and Violence Survivors  
Preventing Crime and Violence*

United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, and Education

**Written Testimony of Chief David Sonntag**

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*on behalf of*

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Submitted for the Record

May 1, 2009

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to submit this written testimony. My name is David Sonntag. I am also a member of FIGHT CRIME: INVEST IN KIDS, an anti-crime group of nearly 5,000 police chiefs, sheriffs, prosecutors, and victims of violence from across the country who have come together to take a hard-nosed look at the research about what really works to keep kids from becoming criminals.

As a police chief I know there is no substitute for tough law enforcement. Across the United States, law enforcement is busy arresting and prosecuting offending juveniles. The most dangerous of these youths are locked up. But I have also seen that handcuffs and bars, alone, will not reduce our communities' crime problems. What we know from our experience, the research backs up: targeted investments in our children can give them a better start in life – so that they don't turn to gangs, drugs, and crime.

The members of Fight Crime: Invest in Kids appreciate the difficult job facing Congress and, in particular, this Appropriations Committee in determining how best to allocate scarce resources in a time of enormous financial challenges facing this country. But our nation cannot afford to shortchange the very programs that have been proven to work. Our families and communities need these programs now more than ever, and our future safety depends on them.

#### **Early Childhood Care and Education**

The early years of life are crucial to a child's brain development. The National Research Council has found that 90 percent of brain development occurs before the age of five. High-quality early care and education for at-risk kids during those critical early years not only can help close the achievement gap; it can also reduce the risk of later crime. In fact, at-risk kids in Chicago left out of the government-funded Child-Parent Center programs were 70 percent more likely to be arrested for a violent crime by age 18, according to a study published in the *Journal of the American Medical Association*. The study of Chicago's Child Parent Centers, which served 100,000 three- and four year-olds, also found that those left out were 67 percent more likely to be held back a grade in school, and 71 percent more likely to have been placed in special education. In another study, at-risk kids who were left out of high quality High/Scope Perry Preschool program were five times more likely to be chronic offenders with five or more arrests by age 27. By age 40, those who did not attend the Perry Preschool program were more than twice as likely to become career offenders with more than 10 arrests, and twice as likely to be arrested for violent crimes. Further, children left out of the program were four times more likely to be arrested for drug felonies by age 40, and seven times more likely to be arrested for possession of dangerous drugs. Children who did participate in the Perry Preschool program were those 31 percent more likely to graduate from high school.

Head Start is the federally-funded national pre-kindergarten program for low-income families that provides early education services for children ages 3 to 5, at a cost of about \$8,000 per child. Research on the short-term impacts of Head Start has often demonstrated only modest effects. However, given the disadvantages



that many poor children face, even these modest improvements are meaningful. For example, a national randomized control trial of Head Start showed that Head Start cut the achievement gap nearly in half for pre-reading skills between Head Start children and the national average for all 3- and 4-year-olds. So Head Start helped low-income children make real strides in catching up academically to their more advantaged peers.

Even more significant than short-term academic progress, are the meaningful impacts Head Start has had on children's lives in the long term. Several studies have demonstrated Head Start's long-lasting effects. These have included decreased grade retention, decreased special education placement, increased high school graduation rates, and reduced crime. For example, one national study found that Head Start increased high school graduation rates by 7 percent for children in the program compared to their siblings not in the program but in other care, and decreased crime by 8.5 percent.

Head Start is already an effective program, and incorporates most of the key features of high-quality early education programs proven to cut crime, such as appropriate class-size and teacher-student ratios, comprehensive and age-appropriate early learning standards, related services (including health referrals), and parent involvement and coaching. Further, under the recent Head Start reauthorization bill (enacted a year ago, but not yet fully funded), a portion of all increased investments in the program will be dedicated to quality improvements which would make the program even stronger, such as increased teacher qualifications so that more teachers have at least Bachelor's Degrees, and enhanced curriculum standards. Currently, Head Start teachers are earning half of what public school teachers earn, so it's difficult to attract and retain more highly-qualified teachers; increased quality improvement funding, once it's appropriated, will help significantly.

Early Head Start was created in 1994, in response to research indicating the developmental importance of the first three years in a child's life. Early Head Start serves both pregnant women and children ages birth to 3, providing guidance, information, parenting support, and direct services. Early Head Start provides services through center-based, home-based, and combination program options.

As with Head Start, the research shows that Early Head Start is effective. The program was evaluated through a randomized study of over 3,000 families participating in 17 Early Head Start programs across the country. Three-year-olds who had participated in Early Head Start, compared to their peers who did not, had higher levels of cognitive and language development, better attention to play, and lower levels of aggressive behavior. Parents who participated in the program, compared with the control group, demonstrated more emotional supportiveness to their children, provided higher levels of language and learning stimulation, and read to their children more. The programs that showed the strongest positive effects were those that implemented all of the federal program performance standards and those that combined home visiting and center-based services.

While Early Head Start has not been in existence long enough to track long-term outcomes, the implications are clear. The finding that participation in Early Head Start results in lower levels of aggressive behavior is especially significant; sixty percent of children with high levels of disruptive, aggressive behaviors in early childhood will manifest high levels of antisocial and delinquent behavior later in life.

North Carolina's Smart Start is a nationally-recognized initiative designed to both help working parents pay for early child care and improve the quality of care by providing educational opportunities, resources, and educational materials for teachers. Low-income children who were not enrolled in early childhood

education centers with North Carolina's Smart Start quality improvement assistance were twice as likely to have behavior problems such as aggressive acts and poor temper control, anxiety, and hyperactivity in kindergarten.

Based on all this evidence of the impact of quality early childhood care and education for at-risk kids, I know that if we are willing to invest now, our communities will save money. But don't just listen to me. An analysis by Arthur Rolnick of the Federal Reserve Bank of Minneapolis showed that the High/Scope Perry Preschool program provided an annual return on investment of 16 percent, after adjusting for inflation. That's a lot better than most investments performed last year. The high quality preschool program saved \$16 for every dollar spent (including more than \$11 in crime savings).

Regrettably, state and federal investments lag far behind the need. Only about half of eligible poor kids in this country are served by Head Start. Fewer than five in 100 of eligible infants and toddlers are in Early Head Start. And we don't do much better with the Child Care and Development Block Grant program, helping only one in seven kids in eligible low income families. I don't have to tell you that until this year funding has been stagnant over the past several years – last year, 150,000 fewer kids received child care assistance than in 2000. The economic recession has further compounded the problem—more kids are eligible for these programs and in need of these services, but unable to access them, and states are cutting back their early care and education investments, due to their budget shortfalls.

While we, as a nation, have just begun to recognize the crucial value of early care and education in generating long-term returns on investment, we seldom view early care and education as a strategy for short-term economic growth. However, in the short term, investing in the early-education sector will support jobs for thousands of low-income women and men, many of whom have their own children to support. There are over 2 million Americans working in the early education workforce. Early childhood care and education are strong job-creation vehicles with a demonstrated economic multiplier effect in the short term. In fact, for every two new jobs created in the childcare sector, an additional job is created in the rest of the economy. In addition, early care and education spending goes primarily toward wages. For example, at least 75% of Head Start funding is spent on staff compensation. Because the workforce is entirely within the U.S., and predominantly low-wage, those salaries will quickly be spent in the workers' local economies.

In addition, investing in early care and education also helps financially struggling young families who would either have to pay budget-busting amounts of tuition for childcare, quit their jobs, or leave their children in dangerous circumstances. People who lose their jobs often end child care arrangements, and need help to pay for child care lest they be stuck in a vicious cycle, unable to look for or accept a job because they don't have the money they need to pay for child care. With 60% of women and 90% of men with children under age 6 employed and an annual cost of \$16,000 a year for full-time care for two young children, struggling families can't afford this on their own.

We are excited by the opportunities afforded by the President's proposal for a new Education Department "Zero to Five" state challenge grant to make targeted investments in quality programs proven to save money and make our communities safer. As indicated in the President's February 26<sup>th</sup> budget document, these grants are aimed at broadening the reach of early care and education programs through increased investments from States and local entities, improving quality, and ensuring a seamless delivery of services.

In the face of increasing unemployment and poverty rates, declining incomes, and the country experiencing an economic recession—and in light of the many short-term and long-term economic benefits, in addition to crime reduction benefits—we can't afford not to invest more now in federal Head Start and child care programs, and the new "Zero-to-Five" state challenge grants. Earlier this year, Congress provided a considerable investment in early care and education through the American Recovery and Reinvestment Act. While I am thankful for this important first step, I know that that this alone is not enough—we must continue to build on this foundation so that we can further reduce the level of unmet need and reach more at-risk youth.

**Therefore, on behalf of thousands of law enforcement leaders around the nation, I urge you to include funding for the President's proposed initiatives for substantially increase funding for early care and education, including \$3 billion for the proposed new Education Department "Zero to Five" state challenge grants to expand and improve early care and education, as well as a further \$1 billion increase in funding for Head Start and Early Head Start, and \$1 billion increase in quality child care. That would constitute the balance (taking into account the \$5 billion in funding included in the American Recovery and Reinvestment Act) of President Obama's pledge to increase federal early care and education funding by \$10 billion in FY10 beyond current levels.**

#### **After School Programs for the "Prime Time for Juvenile Crime"**

In the hour after the school bell rings, violent juvenile crime soars and the prime time for juvenile crime begins. The peak hours for such crime are from 3:00 to 6:00 PM on school days. These are also the hours when children are most likely to become victims of crime, be in an automobile accident, smoke, drink alcohol, or use drugs.

Fortunately, after-school programs that connect children to caring adults and provide constructive activities during these critical hours are among our tools for preventing crime. For example, a study compared five housing projects without Boys & Girls Clubs to five receiving new clubs. At the beginning, drug activity and vandalism were the same. But by the time the study ended, the projects without the programs had 50 percent more vandalism and scored 37 percent worse on drug activity.

More than 14 million children still lack adult supervision after school. **President Obama has pledged to double funding for the 21<sup>st</sup> Century Community Learning Centers (21<sup>st</sup> CCLC) program – the federal government's principal after-school program investment. We urge Congress and this Committee to ensure that is a priority in the Fiscal Year 2010 Labor, Health and Human Services, and Education Appropriations bill.**

#### **Law Enforcement Leaders are United**

The members of FIGHT CRIME: INVEST IN KIDS, along with major national law enforcement associations, have adopted forceful calls for public officials to ensure access to quality early care and education and ensure access to after-school programs. Law enforcement leaders' commitment to putting dangerous criminals behind bars must be matched by Congress' commitment to keep kids from becoming criminals. We urge you to increase our nation's investments in these proven crime-prevention strategies that save lives and taxpayer dollars.

Thank you for this opportunity to present our views on how your Subcommittee can invest in approaches that will reduce crime and make us all safer.

## Friends of the Health Resources and Services Administration (HRSA)

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Washington DC, 20016  
202-777-2513

### Testimony of the Friends of the HRSA Concerning the Health Resources and Services Administration's Budget for Fiscal Year 2010 House Appropriations Subcommittee on Labor, Health and Human Services and Education Submitted for the Record May 1, 2009

The Friends of the Health Resources and Services Administration (HRSA) is a non-profit and non-partisan alliance of more than 140 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. The coalition's principal goal is to ensure that HRSA's broad health programs have continued support in order to reach the populations presently underserved by the nation's patchwork of health services.

Through its programs in every state and thousands of communities across the country, HRSA is a national leader in providing a health safety net for medically underserved individuals and families, including 86.7 million Americans who were uninsured for some or all of 2007-2008; 50 million Americans who live in neighborhoods where primary health services are scarce; more than one million people living with HIV/AIDS, and 34 million vulnerable mothers and children, including children with special health needs. **In the best professional judgment of the members of the Friends of HRSA, to respond to this challenge, the agency will require an overall funding level of at least \$8.5 billion for fiscal year (FY) 2010.**

For several years, HRSA has suffered from relatively level funding, undermining the ability of its successful programs to grow. Our request reflects the minimum amount necessary for HRSA to adequately meet the needs of the populations they serve in FY 2010, especially during these difficult economic times that are causing an increase in demand for HRSA programs and funding. Much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services for all; eliminating health disparities; and rebuilding the public health and health care infrastructure.

The coalition is very appreciative of the \$2.5 billion HRSA received in the American Recovery and Reinvestment Act of 2009 for community health centers and health professions workforce development to prepare our health infrastructure for health system reform. This investment recognizes the critical role HRSA plays in building the foundation for health service delivery. However, we urge the Subcommittee to support adequately funding all of HRSA's broad health programs and ensure that vulnerable populations transition smoothly into a new health system and receive continued, quality health services. By supporting, planning for and adapting to change, we can build on the successes of the past and address the new gaps that emerge as a result of health system reform.

Our \$8.5 billion funding request is based on recommendations provided by coalition members for the various programs they focus on. It includes \$2.602 billion for the Health Centers program, the fully authorized level under the Health Care Safety Net Act of 2008, as part of a long-term plan to provide care to 30 million Americans by 2015. Thanks to the leadership of the Subcommittee, more than 7,000 health centers in every state and territory provide a health care home for more than 18 million medically underserved and low-income patients, and demand for their services continues to grow. The Health Centers program targets populations with special needs, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing. Health centers provide access to

high-quality, family-oriented, culturally and linguistically competent primary care and preventive services, including mental and behavioral health, vision, and dental services. While recent growth in the health centers program has been substantial, a significant need remains in underserved communities across the country. We strongly encourage the Subcommittee to continue its support of existing health centers and efforts to expand the reach and scope of the Health Centers program into new communities.

Coalition members recommend \$235 million for the National Health Service Corps (NHSC), the amount authorized under the Health Care Safety Net Amendments of 2002. Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. The Corps supports the recruitment and retention of primary care clinicians to practice in underserved communities in exchange for scholarships and loan repayment. The Corps supports over 4,000 clinicians, with over half working in community health centers. Growth in the Health Centers program must be complemented with growth in the recruitment and retention of primary care clinicians to ensure adequate staffing.

Coalition members recommend \$550 million for health professions programs under Title VII and VIII of the Public Health Service Act. These programs are an essential component of America's health safety net and work in concert with the Health Centers Program and National Health Service Corps to enhance the supply, distribution and diversity of the health professions workforce. They are the only federal programs that support the education and training of primary care providers in interdisciplinary settings to work in underserved communities and increase minority representation in the health professions workforce. Through loans, scholarships and grants to academic institutions and non-profit organizations, these programs provide support for the training of primary care physicians, nurses, dentists, optometrists, physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, pharmacists, health educators, and other allied health providers. Adequate funding will reduce provider shortages in rural, medically underserved and federally designated health professions shortage areas and strengthen the pipeline of new providers that Health Centers and other safety-net health facilities need to meet the long-term needs of underserved communities. In addition, we recommend funds be appropriated to re-establish the National Center for Health Workforce Analysis to conduct and support statistical and epidemiological activities for assessing and improving decision-making to enhance the supply, distribution, diversity, and development of the current and future public health workforce. Finally, we urge the Committee to provide funding for the grant program under section 758 of the Public Health Service Act to develop interdisciplinary training and education programs on domestic violence and other types of violence and abuse as authorized by the Violence Against Women and Department of Justice Reauthorization Act of 2005.

We recommend \$330 million for the Children's Hospital Graduate Medical Education (GME) Program, the amount authorized under the Children's Hospital GME Support Reauthorization Act of 2006. This program provides funds to freestanding children's hospitals to support the training of pediatric and other residents in GME programs. This program ensures that pediatric hospitals receive federal funding comparable to other types of hospitals. We also request a significant investment in the Patient Navigator program that places navigators in underserved communities to help people with cancer and/or other chronic diseases make their way through the health systems and utilize community services that will help them beat chronic disease for longer, healthier lives.

We recommend \$850 million for the Maternal and Child Health (MCH) block grant, the fully authorized level under Title V of the Social Security Act. For over 70 years, the MCH block grant has provided a source of flexible funding for states and territories to address their unique needs related to improving the

health of mothers, infants, children, adolescent, and children with special health care needs. Today, this program provides prenatal services to over two million mothers—almost half of all mothers who give birth annually—and primary and preventive care to over 17 million children, including almost one million children with special needs. Fully funding the MCH block grant will enable states to expand critical health services and cope with ever increasing medical costs.

Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal, and functional conditions in newborns. Screening detects heritable disorders in newborns that, if left untreated, can cause disability, mental retardation, serious illnesses, or even death. While nearly all babies born in the U.S. undergo newborn screening for genetic birth defects, the number of these tests varies from state to state. We recommend \$30 million for the Heritable Disorders Program to support state efforts to improve programs, to acquire innovative testing technologies, and to increase capacity to reach and educate health professionals and parents on newborn screening programs and follow-up services. These activities and the funding level are authorized by the Newborn Screening Saves Lives Act.

We recommend \$16 million for the Traumatic Brain Injury (TBI) program in order to better serve the 5.3 million Americans with a long-term or lifelong need for help to perform daily activities as a result of a TBI, including many of our returning war veterans. The TBI Program provides grants to states to coordinate, expand and enhance service delivery systems in order to improve access to services and support for persons with TBI and their families. The TBI program also provides funds to state protection and advocacy programs that work to ensure that people with TBI get access to the supports and services they need.

We recommend \$25 million for the Emergency Medical Services for Children (EMSC) program to address significant shortcomings in pediatric emergency care. The EMSC program is a national initiative designed to reduce child and youth disability and death due to severe illness and injury. EMSC grants provide funding for states and territories to improve existing emergency medical services systems and develop better procedures and protocols for treating children. Additional funding is needed to maintain and improve the program's activities, take advantage of important opportunities and address emerging threats such as terrorism.

We recommend \$2.816 billion for the Ryan White HIV/AIDS programs, which is the estimated amount necessary to provide health services to all eligible individuals. The Ryan White programs provide the largest source of federal discretionary funding to support health services for more than 500,000 low-income, uninsured and underinsured people living with HIV/AIDS. Through grants to state and local governments and community-based organizations, the Ryan White HIV/AIDS programs support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide training for health professionals treating people with HIV/AIDS; provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; and address the disproportionate impact of HIV/AIDS on women and minorities. A significant funding increase is needed to meet growing medical costs and incidence of HIV, particularly among underserved populations.

The Office of Rural Health Policy promotes better health services for the 60 million Americans who live in rural communities. These communities suffer from inadequate access to quality health services and experience the higher rates of illness associated with lower socioeconomic status. Rural Health Outreach and Network Development Grants, and other programs are designed to support community-based

disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas. In addition, Rural Health Research Centers help policymakers better understand the challenges that rural communities face in assuring access to health services and improving the health of their residents. Finally, the Rural and Community Access to Emergency Devices Program provides states with grants to train lay rescuers and first responders to use automated external defibrillators (AEDs) and purchase and place them in public areas where sudden cardiac arrests are likely to occur. We encourage the Subcommittee to adequately fund these important programs that address the many unique health service needs of rural communities.

We recommend \$700 million for the Family Planning programs under Title X of the Public Health Service Act. Title X programs provide comprehensive, voluntary and affordable family planning services to nearly five million low-income women at more than 4,500 clinics nationwide. Title X funded clinics help improve access to contraceptives, which help women plan the number and timing of their pregnancies, improve maternal and infant health, and help to prevent approximately 1.94 million unintended pregnancies each year, including nearly 400,000 teenage pregnancies. The Guttmacher Institute estimates that unintended pregnancies prevented each year would have resulted in 810,000 abortions and without publicly funded family planning programs, the U.S. abortion rate would be nearly two-thirds higher than the current level. Family planning is also cost-saving and for every public dollar invested in family planning, \$3.80 is saved in costs associated with unintended births to women who are eligible for Medicaid. Today, almost 17 million women need publicly supported contraceptive care – a number which continues to grow. Title X programs require a substantial increase in investment to meet the growing demand.

The Healthcare Systems Bureau provides national leadership on the transplantation of organs, bone marrow and cord blood. The recently-passed Budget Resolution Conference Agreement calls for increased funding for “the organ transplant program.” Coalition members recommend \$35 million for the Division of Transplantation in order to meet the Office of Management and Budget’s goal of doubling the number of transplants by 2013 and reduce the waiting list of 101,951 people in need of a life saving organ transplant. We recommend \$38 million for the C.W. Bill Young Cell Transplantation Program, the amount authorized by the Stem Cell Therapeutic and Research Act of 2005. This program helps patients who need a potentially life-saving bone marrow or cord blood transplant, including patients with diseases like leukemia, lymphoma, sickle cell anemia, or other inherited metabolic or immune system disorders. We also recommend the fully authorized \$15 million for the National Cord Blood Inventory, which collects and maintains high-quality cord blood units and makes them available for transplantation through the C.W. Bill Young Cell Transplantation Program.

Poison Control Centers, also administered by the Healthcare Systems Bureau, are a critical resource for people, health professionals and organizations. Poisoning can happen to anyone, at anytime in any place and can lead to serious illness or even death. Each year, more than two million possible poisonings are reported to the nation’s poison centers. On average, poison centers handle one possible poisoning every 13 seconds. These critical centers cannot afford to lose any resources and we encourage the subcommittee to fully fund this program.

Finally, we recommend a significant funding increase for HRSA’s program management and staffing needs. Since 2001, HRSA has experienced a decline of almost 600 full-time equivalent employees. While HRSA has continued to administer its many programs effectively, the agency is facing ever growing demands as a result of the economic crisis and a changing health system. We strongly urge the

Subcommittee to increase program management funds to provide the agency with the necessary human and other resources to ensure the programs it administers are effective and improve the health of the American public.

We appreciate the Subcommittee's hard work in advocating for HRSA's programs in a climate of competing priorities. The members of the Friends of HRSA thank you for considering our **FY 2010 request for \$8.5 billion for HRSA** and are grateful for this opportunity to present our views to the Subcommittee.



Academic Pediatric Association	American Medical Women's Association
Advocates for Youth	American Nephrology Nurses' Association
AIDS Action	American Nurses Association
AIDS Alliance for Children, Youth and Families	American Occupational Therapy Association
AIDS Foundation of Chicago	American Optometric Association
The AIDS Institute	American Pediatric Society
AIDS Project Los Angeles	American Physical Therapy Association
The Alan Guttmacher Institute	American Podiatric Medicine Association
Allergy and Asthma Network Mothers of Asthmatics	American Psychiatric Association
Alliance for Academic Internal Medicine	American Psychological Association
American Academy of Family Physicians	American Public Health Association
American Academy of Nurse Practitioners	American Red Cross
American Academy of Nursing	American School Health Association
American Academy of Ophthalmology	American Society for Microbiology
American Academy of Pediatrics	American Society for Reproductive Medicine
American Academy of Physician Assistants	Americans for Democratic Action
American Association of Colleges of Podiatric Medicine	The Arc
American Association for Dental Research	Asian and Pacific Islander American Health Forum
American Association of Colleges of Nursing	Association for Prevention Teaching and Research
American Association of Colleges of Osteopathic Medicine	Association of Academic Health Centers
American Association of Colleges of Pharmacy	Association of American Medical Colleges
American Association of Family and Consumer Services	Association of American Veterinary Medical Colleges
American Association of Nurse Anesthetists	Association of Clinicians for the Underserved
American Association of Orthopedic Surgeons	Association of Departments of Family Medicine
American Association on Intellectual and Developmental Disabilities	Association of Family Medicine Residency Directors
American Cancer Society	Association of Maternal and Child Health Programs
American College of Nurse-Midwives	Association of Medical School Pediatric Department Chairs
American College of Obstetricians and Gynecologists	Association of Minority Health Professions Schools
American College of Physicians	Association of Organ Procurement Organizations
American College of Preventative Medicine	Association of Professors of Medicine
American Counseling Association	Association of Public Health Laboratories
American Dental Association	Association of Reproductive Health Professionals
American Dental Education Association	Association of Schools of Allied Health Professionals
American Dental Hygienists' Association	Association of Schools of Public Health
American Dietetic Association	Association of State and Territorial Directors of Nursing
American Federation of State, County and Municipal Employees	
American Foundation for AIDS Research	
American Heart Association	
American Hospital Association	
American Medical Student Association	

- Association of State and Territorial Health Officials  
 Association of University Centers on Disabilities  
 Association of Women's Health, Obstetric and Neonatal Nurses  
 Avancer Health Policy  
 CAEAR Coalition  
 Catholic Health Association of the U.S.  
 Center for Health Policy Research and Ethics, GMU  
 Center for the Advancement of Health  
 Center for Women Policy Studies  
 Center on Disability and Health  
 Charles Drew University  
 Children's Defense Fund  
 Coalition for American Trauma Care  
 Coalition for Health Funding  
 Coalition for Health Services Research  
 Consortium of Social Science Associations  
 Council of Accredited MPH Programs  
 Easter Seals  
 Emergency Nurses Association  
 Epilepsy Foundation  
 Families USA  
 Family Violence Prevention Fund  
 Health and Medicine Counsel of Washington  
 HIV Medicine Association  
 Human Rights Campaign  
 Infectious Diseases Society of America  
 Institute for Children's Environmental Health  
 Latino Council on Alcohol and Tobacco  
 Legal Action Center  
 March of Dimes  
 Meharry Medical College  
 Morehouse School of Medicine  
 NAADAC, the Association for Addiction Professionals  
 National AHEC Organization  
 National Alliance of State and Territorial AIDS Directors  
 National Assembly on School-Based Health Care  
 National Association of Addiction Treatment Providers  
 National Association of Community Health Centers  
 National Association of Councils on Developmental Disabilities  
 National Association of County and City Health Officials  
 National Association of Local Boards of Health  
 National Association of People with AIDS  
 National Association of Public Health Statistics and Information Systems  
 National Association of Public Hospitals and Health Systems  
 National Association of Rural Health Clinics  
 National Association of Social Workers  
 National Associations of Children's Hospitals  
 National Black Nurses Association  
 National Coalition for the Homeless  
 National Council for Diversity in the Health Professions  
 National Council of La Raza  
 National Disability Rights Network  
 National Episcopal AIDS Coalition  
 National Family Planning and Reproductive Health Association  
 National Health Care for the Homeless Council  
 National Hemophilia Foundation  
 National Hispanic Medical Association  
 National League for Nursing  
 National Marrow Donor Program  
 National Medical Association  
 National Minority AIDS Council  
 National Network for Youth  
 National Rural Health Association  
 North American Primary Care Research Group  
 Oncology Nursing Society  
 Organizations of Academic Family Medicine  
 Partnership for Prevention  
 Planned Parenthood Federation of America  
 Sexuality Information and Education Council of the United States  
 Society for Adolescent Medicine  
 Society for Pediatric Research  
 Society for Public Health Education  
 Society for the Psychological Study of Social Issues  
 Society of General Internal Medicine  
 Society of Teachers of Family Medicine  
 Trust for America's Health  
 U.S. Conference of Mayors

Testimony of the Friends of NICHD

Fiscal Year 2010 Appropriations -- Eunice Kennedy Shriver National Institute of Child Health and Human Development

May 1, 2009

Submitted by: Emil Wigode, Chair, Friends of NICHD

March of Dimes Foundation

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The Friends of the National Institute of Child Health and Human Development (NICHD) is a coalition of more than 100 organizations, representing scientists, physicians, health care providers, patients, and parents, concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to submit testimony to support the extraordinary work of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.

The Coalition would like to thank Chairman Obey, Ranking Member Tiahrt, and the entire Congress for the unprecedented \$10.4 billion provided for the National Institutes of Health (NIH) in the American Recovery and Reinvestment Act (ARRA). The next step is to build on this investment through predictable and sustained, long-term growth in NIH funding in the FY 2010 budget and beyond. **To ensure that progress in basic, translational and clinical research is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting a FY 2010 appropriation of at least \$32.4 billion, an increase of \$2.1 billion (7 percent).**

The Coalition has a particular interest in the important research conducted and supported by the NICHD. Since its establishment in 1963, the NICHD has made great strides in meeting the objectives of its broad biomedical and behavioral research mission. The NICHD research mission and portfolio includes a focus on women's health and human development, including research on child development, before and after birth; maternal, child, and family health; reproductive biology and population issues; and medical rehabilitation.

Although the NICHD has made significant contributions to the well-being of children, women, and families, much remains to be done. With sufficient resources, the NICHD could build upon the promising initiatives described in this testimony and produce new insights into human development and solutions to health problems for the world and for the nation – including the families who live in your districts. **For FY 2010, the Friends of NICHD support an appropriation of at least \$1.386 billion for NICHD, a 7 percent increase over FY 2009.**

**New Discoveries**

Adding to its strong record of progress over the past 45 years, recent advances by the NICHD towards its mission objectives have especially contributed to the health and well-being of our nation and our world. We are proud to highlight some of them here.

**Tracking Brain and Behavioral Development:** The NICHD is one of the leading Institutes in the NIH Magnetic Resonance Imaging (MRI) Study of Normal Brain Development. The

purpose of this study is to track brain and behavioral development in 500 healthy children from diverse geographic, socioeconomic and ethnic backgrounds from birth to age 18. According to the latest findings, children appear to have reached adult levels of performance on basic cognitive and motor skills by age 11 or 12. The long-term goal of the study team is to link these behavioral data to MRI scans of the children's brains. Together, the two data sets will allow researchers to view how the brain grows and reorganizes itself throughout childhood, and to explore the meaning of the structural changes they see. The database will also serve as a reference post for scientists to better understand what goes wrong in children with genetic disorders, language and learning difficulties, prenatal exposure to alcohol or drugs or other brain injury.

**New Pediatric Seizure Study:** Last year, the NICHD announced plans for a new study into the safest and most effective treatment for pediatric seizures, or status epilepticus, which affects between 50,000 to 60,000 children in the United States each year. Status epilepticus may occur in patients with epilepsy or in patients without epilepsy who experience a seizure due to a high fever, low blood sugar, an infection of the central nervous system, or a head injury. Children who have no apparent risk factors may also develop status epilepticus. Currently, there are two drugs in use, diazepam and lorazepam, but there is no large-scale comparison study to show which one is preferable under which conditions. The study is the most comprehensive of its kind and 11 hospitals around the country will participate. The NICHD is funding the study in accordance with the **Best Pharmaceuticals for Children Act (BPCA)**, under which NIH consults with the U.S. Food and Drug Administration to determine which approved drugs should be prioritized for further testing in children.

**Unraveling Genetic Basis of Autism:** NICHD is capitalizing on advances in genetics research by participating in the Autism Genome Project (AGP), a public-private collaboration involving more than 120 scientists and 50 institutions in 19 countries. The first study to emerge from AGP implicated components of the brain's glutamate chemical messenger system and a previously overlooked site on chromosome 11. Based on 1,168 families with at least two affected members, the genome scan also adds to evidence that tiny, rare variations in genes may heighten risk for autism spectrum disorders. The spectrum of disorders collectively known as autism affects as many as one in 150 Americans resulting in impaired thinking processes, emotional and social abilities, and motor control. With NIH support, the AGP is pursuing studies to identify specific genes and gene variants that contribute to vulnerability to autism. These include explorations of interactions of genes with other genes and with environmental factors, and laboratory research aimed at understanding how candidate susceptibility genes might work in the brain to produce the disorders.

**Vaccine Shows Promise in Reducing Stillbirth:** An estimated 40,000 children are born each year in the United States with the cytomegalovirus (CMV). CMV is a common virus that most Americans are exposed to at some point in their lives; however, it is linked to stillbirth and can also cause mental retardation, cerebral palsy and hearing loss in newborn children. NICHD researchers are working to develop a vaccine for women of childbearing age to reduce the risks of CMV in pregnancy. Scientists found in their prototype research that vaccinated guinea pigs had significantly less amounts of the virus in their blood than the control group and their offspring were more likely to survive as well as have higher birth weights. This basic animal research is the first step towards developing a vaccine for use in human populations.

**Impact of Child Care:** The NICHD Study of Early Child Care and Youth Development, the largest, longest running, and most comprehensive study of child care in the United States, continues to provide information about the long-term impacts of child care on child development. A recent study funded by the NICHD, and other federal agencies, demonstrated that it is possible to teach preschoolers the pre-reading skills they need for later school success, while at the same time to foster the social skills necessary for making friends and avoiding conflicts with their peers. This important research will help inform parents and educators, as well as shape policy-making decisions regarding programs such as Head Start.

**Magnesium Sulfate to Prevent Cerebral Palsy:** Research conducted by investigators in 20 participating research centers of the Maternal Fetal Medicine Units Network of the NICHD found that preterm infants born to mothers receiving intravenous magnesium sulfate—a common treatment to delay labor—are less likely to develop cerebral palsy than are preterm infants whose mothers do not receive it. Cerebral palsy is a neurological disorder affecting control of movement and posture and limits activity. The brain may be injured or develop abnormally during pregnancy, birth or in early childhood. The use of magnesium sulfate to reduce the risk of cerebral palsy is a major advance and the data from this study will help obstetricians make informed treatment decisions for the women under their care.

#### **Future Research Opportunities**

Although the studies mentioned above have unquestionably made significant contributions to the well-being of our children and families, there is still much to discover about ways to improve health, learning, and quality of life. Progress in the following research areas can only be achieved with adequate federal investments.

**Contraceptive Research:** Of the approximately 6 million pregnancies in the U.S. each year, approximately one-half are unintended. The NICHD conducts contraceptive research and development to provide safe and effective methods of preventing unintended pregnancies and to help women time and space the birth of their children. More research is also needed to find the cause for lower efficacy in hormonal contraceptives among overweight and obese women.

**Education and School Readiness Research:** NICHD continues to build on its impressive portfolio of research on how children acquire the emotional, social and academics skills necessary to succeed in school and beyond; however more work is needed in four particular areas: (1) More research is needed to understand how neurological processing disorders impact learning and literacy, particularly in reading comprehension for grades 4-8, so that early intervention may improve learning and academic outcomes for young adults. (2) English language learners are the fastest growing population in the U.S. We need to better understand how to make the distinction between learning delays caused by language barriers versus possible learning disabilities in school-age children. (3) Too little is still known about math disabilities including where they reside in the brain, how they impact learning over time and what we can do to remediate and intervene with those who have them. More recent programs of math and science cognition, as well as math learning disabilities, will inform the nation's innovation agenda and ensure a competitive workforce. (4) NICHD is also currently funding new initiatives to develop better measures of the social and emotional bases of school readiness, which will inform our early education programs.

**Family Research:** As the family is the primary context for child development, the NICHD has played a significant role in examining the dramatic changes in family structure in the United States over the last 40 years. Scientists are currently focused on developing new study designs to better understand the family processes that transcend the traditional home environment, including the role of absent fathers, the contributions of grandparents and others outside the immediate family. Recognizing that so many parents are also in the workforce, NICHD is moving forward on its Work, Family, Health and Well-Being Initiative. The long-range goals of the initiative are to identify workplace interventions that can improve health by improving the ability of the worker to successfully meet both work and family demands.

**HIV/AIDS:** NICHD research is focused on testing and refining effective interventions to slow HIV progression in women, to treat infected infants, and to reduce mother-to-child transmission. NICHD collaborative research efforts on interventions, such as drug therapy, have reduced maternal transmission of HIV from 25 percent to 1.2 percent worldwide. Until vaccines and cures for HIV are a reality, prevention of infection must rely upon individuals practicing protective behavior. NICHD research is needed to examine the psychological and social factors that influence an individual's decision-making and behaviors that reduce the risk of HIV infection or transmission, such as using condoms, avoiding sexual intercourse with infected individuals, and avoiding drug use that may lead to unsafe sexual practices or needle sharing.

**Hydrocephalus:** More research needs to be done into the many complex issues surrounding hydrocephalus for the 200,000 children under 18 now living with this condition, ranging from obvious medical concerns due to repeated brain surgeries, to less well understood challenges involving learning disabilities of children with hydrocephalus, motor and sensory impairment, and socialization challenges.

**Intellectual and Developmental Disabilities:** Ongoing support of the research in mental retardation and developmental disabilities being undertaken at the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC) is essential. Many disorders are being studied by the IDDRC such as Down syndrome, Fragile X syndrome, Rett syndrome, and autism. Genetic and biomedical advances over the past few years hold the promise for understanding the threats to healthy and full development and ultimately to the prevention and amelioration of the impact of many disabilities.

**National Children's Study:** The Children's Health Act of 2000 charged NICHD with leading the National Children's Study (NCS). NCS is a national longitudinal study of environmental influences on the health and development of children and adolescents. It will follow 100,000 children from before birth to early adulthood, providing one of the richest information resources available for answering questions related to children's health and development. The Friends of NICHD thanks the Committee for funding the NCS through the NIH Office of the Director in FY 2009, and urges the Committee to provide at least \$192 million for the Study in FY 2010.

**Natural and Man-made Disasters:** NICHD is poised to partner with other NIH Institutes and Centers to encourage more research on the social and behavioral implications of natural and man-made disasters. More research is necessary to understand fully how these disasters affect, in particular, vulnerable populations including children and people with special needs.

**Obesity:** NICHD is integrally involved in research into the origins of obesity in childhood. Next to tobacco use, diet and exercise represent the areas in which prevention efforts will

have the greatest impact in reducing the socioeconomic and societal burdens of the obesity epidemic. More developmental research needs to be focused on understanding the interplay among behavioral, social and physical environment, and biological factors that lead to obesity so that effective and appropriate interventions can be developed earlier in the life cycle.

**Preterm Birth:** Preterm birth is a serious and growing public health problem that affects more than 500,000 babies each year. It is the leading cause of neonatal death and about half of all premature births have no known cause. A key strategy recommended by the Institute of Medicine and experts convened for the Surgeon General's Conference on the Prevention of Preterm Birth is to create integrated transdisciplinary research centers to build the knowledge base needed for development of effective interventions to prevent prematurity. These new centers would serve as a national resource for investigators to design new research approaches and strategies to address the serious and growing problem of preterm birth.

**Rehabilitation Research:** The NICHD houses the National Center for Medical Rehabilitation Research (NCMRR). This Center fosters the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities. A primary goal of Center-supported research is to bring the health related problems of people with disabilities to the attention of the best scientists in order to capitalize upon the myriad advances occurring in the biological, behavioral, and engineering sciences.

**SIDS:** Though the NICHD has made remarkable progress in reducing the rate of SIDS, SIDS remains the leading cause of death in infants from one month of age to one year. More research and public education is needed to address the large number of babies dying of asphyxiation and suffocation in unsafe adult bed-sharing situations. Additional support is also needed to expand the work of NICHD's Stillbirth Collaborative Research Network, where for the first time we are finding answers that may ultimately lead to prevention of many of these 26,000 devastating losses, many of which are late term and yet unexplained.

#### **Conclusion**

The potential contributions of the Institute to the lives of countless individuals are limited only by the resources available for carrying out its vital mission. **This is why the Friends of NICHD ask you to provide an appropriation of \$1.386 billion to the Institute.** Our nation and the world will continue to benefit from your promise to improving health and scientific advancement long after the doubling effort is over.

We thank you, Mr. Chairman, and the Committee, for your support of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and thank you for the opportunity to share these comments.

## Written Testimony

### **FY10 Funding: National Institute for Dental and Craniofacial Research**

Prepared for presentation to the U.S. House of Representatives  
Appropriations Subcommittee on  
Labor, Health & Human Services, Education, and Related Agencies

*Submitted By:*

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President,

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April 30, 2009

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Mr. Chairman and distinguished Members of the Subcommittee, the members of the **Friends of the National Institute of Dental and Craniofacial Research (FNIDCR)**, a leading broad-based coalition of individuals, academic institutions, patient advocate groups, dental societies, and corporations, that understands the importance of dental, oral and craniofacial health to our society, are requesting that FY10 funding for the **National Institute of Dental and Craniofacial Research (NIDCR)** be appropriated at our recommended level of \$442 million.

Currently, FY09 funding for NIDCR is \$402,652,000. This is a welcomed 3.32 percent increase from the stagnated funding levels of the previous five fiscal years. The American Recovery and Reinvestment Act of 2009 included \$10 billion in aid to the National Institutes of Health (NIH) of which approximately \$100 million will be appropriated to NIDCR. FNIDCR is grateful and has applauded this unprecedented financial support of medical research and science.

However, to maintain a majority of the scientific work that will commence as a result of the temporary two-year stimulus aid, we respectfully request a 10 percent increase for NIDCR for FY10. A 10 percent increase will ensure that researchers will be able to continue their work after stimulus funding expires at the end of FY10. And although NIH's budget has doubled since 1999, NIDCR's budget has not. In fact, NIDCR's percentage of total NIH funding has decreased during that time, going from 1.5 percent to 1.33 percent.

#### **NIDCR: A Renown Leader in Research**

For 61 years, NIDCR has been the leading sponsor of research and research training in biomedical and behavioral sciences. Its mission is to *"improve oral, dental and craniofacial health through research, research training, and the dissemination of health information."*



NIDCR meets its mission by:

- Performing and supporting basic and clinical research;
- Conducting and funding research training and career development programs to ensure an adequate number of talented, well-prepared and diverse investigators is sustained;
- Coordinating and assisting relevant research and research-related activities among all sectors of the research community; and
- Promoting the timely transfer of knowledge gained from research and its implications to health professionals, researchers, and policy-makers; and on the overall well-being of our society.

In addition, NIDCR's Gold Standard Peer Review System ensures that taxpayers' dollars are being utilized in a wise, effective and productive manner.

#### **NIDCR Research Benefits Society**

Proper federal funding of NIDCR will transform the future of medical and dental practice to the benefit of our society and ease the burden on our nation's healthcare system. Examples of where NIDCR research has benefited, and will continue to benefit, society are:

***Tooth Decay:*** Fluorides and sealants have cut the rate of the number of American adults, aged 45 and older, who are without teeth by more than half since the 1950s. Government investment in oral health research saved Americans \$3 for every \$1 invested.

***Oral Cancer Detection:*** In his speech to a Joint Session of Congress, President Barack Obama spoke of a new effort to conquer cancer by seeking a cure in our lifetime. Oral cancer affects 38,000 Americans each year and approximately 22 Americans die each day from it. Survival rates are among the lowest of all the major cancers. It is difficult to detect and hard to predict its outcome. However, if detected in early stages, the five-year survival rate is 83 percent. NIDCR-supported research has yielded initial success with developing new diagnostic techniques that can lead to early detection and life-saving interventions. For example, oral cancer is the first cancer to have its biomarkers mapped using Salivary Diagnostics (see below), and the presence of these biomarkers resulted in an early diagnosis of oral cancer 93 percent of the time. Furthermore, as a testament to scientific discoveries, oral researchers have confirmed that oral cancer (traditionally thought of as being driven by extensive use of tobacco and alcohol) possesses a strong and growing link to Human Papilloma Virus (HPV).

***Salivary Diagnostics.*** The promising prospect of using saliva as a diagnostic fluid to identify a number of emerging diseases, such as cancer, HIV/AIDS, and heart disease, is an example of the type of cutting-edge research being conducted and supported by NIDCR. Salivary Diagnostics, a non-invasive

process, possesses advantages over traditional blood testing, including the absence of needles and the ability to be administered on-the-spot, yielding results in 10 minutes.

**Genome-wide Association Studies:** NIDCR is supporting the first genome-wide association studies on cleft lip/cleft palate and dental carries. This is being done in collaboration between epidemiologists, geneticists, informatics experts, and environmental scientists. The studies offer significant potential for understanding the molecular and genetic basis of cleft lip/cleft palate and dental carries with the goal of improving the ability to predict and manage them.

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease
- Chronic Dry Mouth
- Chronic Facial and Oral Pain, and
- Bone and Cartilage Regeneration

#### **NIDCR Research Makes a Difference in People's Lives**

Because FNIDCR is a broad-based coalition of members, we are able to share first-hand perspectives from across the spectrum of the oral health community.

#### ***National Foundation for Ectodermal Dysplasias:***

For several decades, individuals affected by ectodermal dysplasia (ED) have benefited from NIDCR-funded research using osseointegrated implants to correct problems with edentulism. That research was further validated by a recent retrospective study that concluded that such implants continue to be a safe and effective treatment. While former research is of great interest, it is the need for additional research that must be given consideration. For example, there has not been substantive research which supports or negates the value of materials used for augmentation of the alveolar ridge prior to placement of implants. As a result, patients are often the "guinea pigs" for clinicians, subjecting the patient to augmentation, failure, or infection. While NIDCR has been invaluable in moving ectodermal dysplasia research forward, additional funding is necessary to help address past research funding shortfalls to meet the mission of NIDCR.

#### ***Sjogren's Syndrome Foundation:***

NIDCR has given much-needed hope to approximately four million Americans who suffer from Sjögren's syndrome, the second most common autoimmune connective tissue disease. Sjögren's affects the moisture-producing glands, resulting in dry eye and dry mouth, and can involve any body organ or system leading to serious health consequences and a major impact on quality of life. Sjögren's is a disease that crosses many specialties and was largely ignored by investigators until the NIDCR established a Sjögren's clinic and became a leader to catalyze research into this complex disease. Recently, NIDCR funded an international registry that will help us better understand Sjögren's and offer bio-specimens to researchers from around the world. NIDCR also issued a Request

for Applications in Sjögren's that has jumpstarted critical areas of research such as identification and elucidation of salivary and serum biomarkers and immune and genetic factors that contribute to disease development. NIDCR has helped make scientific workshops possible on topics such as Sjögren's and lymphoma, which most frequently occurs in the salivary glands, leading to greater interest in this topic and collaborations among Immunologists, Oncologists, and Pathologists. Thanks to the active leadership of NIDCR, Sjögren's syndrome is finally receiving the recognition it deserves as a leading autoimmune disease and is on the verge of novel discoveries during this new era of medical research.

***University of Maryland College of Dental Surgery:***

Maryland's research thrusts are oropharyngeal cancer, a leading cause of death, chronic orofacial pain, and emerging as well as disfiguring infections, including MRSA. At Maryland, NIH-NIDCR support constitutes the backbone for fulfilling its mission to nurture new and to stimulate existing talent in these important areas of unmet need. It provides the resources to develop and maintain a state-of-the-art research infrastructure that is globally competitive and signals to the rest of the world the commitment of the U.S. to reduce the burden of disease for all people. It provides the knowledge for advancing professionals that will offer first-rate care to patients. NIH-NIDCR funding also contributes to Maryland's research training workforce pipeline in the form of training grants so that new investigators and related personnel can enter this field of discovery. Finally, it enables Maryland, by means of science, to develop and launch exciting new programs that improve the access to dental care while fostering a culture for better and safer dental treatments for all Americans.

***University of Michigan School of Dentistry:***

Research and discovery is deeply embedded in the culture of the University of Michigan School of Dentistry. It has consistently ranked among the top 3 schools in receipt of NIDCR grant awards over the past 5 years, during which NIDCR has provided approximately 68% of total research funding. Focused on a broad range of oral health issues, The School of Dentistry has identified its research strengths through theme groups that are predominately funded through NIDCR, including Developmental Craniofacial Biology, Neurobiology, Tissue Engineering and Regeneration, Cancer Biology and Microbiology/Immunology/Inflammatory Diseases. NIDCR support of our basic and clinical research programs has enabled The School's scientists to make a tangible positive difference in the health and welfare of the citizens of the state of Michigan and the broader community nationwide. Major scientific impacts resulting from this funding include: uncovering the biological basis of the relationship between periodontal disease and diabetes; development of a method of gene delivery that appears safe for regenerating tooth-supporting periodontal tissues; advancing the understanding of inherited enamel defects; and the development of biologic substitutes for regenerating tissues and organs that can be then transplanted during reconstructive surgery. NIDCR has enabled the University of Michigan School of Dentistry to make a difference in the lives of those it serves.

#### **Funding Medical Research Generates Economic Activity**

We contend that a 10 percent increase in FY10 NIDCR funding also helps to sustain the increased economic activity generated by ARRA throughout the nation.

At a public policy forum in November 2008, Former NIH Director Dr. Harold Varmus, who President Barack Obama eventually selected as one of his science advisers, made the case that stimulus aid to NIH would provide, in essence, a stimulus to the economy. In short, it would:

- Pay salaries of scientists, technicians, graduate students
- Pay for indirect costs of universities to function
- Go toward the purchase of supplies, small equipment, all of which are made by US manufacturers.

**To speak further to Dr. Varmus' point, please take into consideration that \$22 billion in NIH funding generates more than \$50 billion in economic activity.**

Moreover, NIDCR-funded research has a presence in 200, or 46 percent, of Congressional Districts and in 45 states. Therefore, a significant portion of NIDCR-funded research occurs off-campus and around the country.

#### **Oral Health Disparities Centers**

Finally, through community-based disparities research funded by NIDCR, a difference is being made in meeting the health needs of our nation's low-income, underserved, and high-risk populations. Sadly, this need was made apparent with the tragic passing of 12-year-old Deamonte Driver who died from a tooth infection in 2007.

NIDCR is committed to eventually eliminating oral health disparities by planning to fund Centers to Reduce Oral Health Disparities this summer. The Centers will continue to perform interventions to determine the best methods for preventing oral disease and applying research findings in communities with health disparities.

#### **RECOMMENDATION**

Simply stated, proper funding of the National Institute for Dental and Craniofacial Research is essential to the overall health and well-being of our fellow Americans. Moreover, we firmly contend that medical discoveries and advances from NIDCR funding lead to improvements in dental practices and change the scope of public health policies across the nation. Whether it is detecting a clear link between bacteria in the mouth and heart disease—or discovering how saliva can be used to detect early indications of disease—we all benefit when we make oral health research a priority.

Therefore, based upon the merits of the research conducted by NIDCR and its demonstrated benefits to the lives of countless Americans in all parts of the United States, **we respectfully request the Subcommittee fund NIDCR at \$442 million for FY10 so that it can realize the full potential of its worthy mission and continue the scientific research that will emerge as a result of ARRA.**

Thank you for the opportunity to present our written testimony before the Subcommittee.

**Friends of the National Institute on Aging  
Testimony on FY 2010 National Institutes of Health Appropriations**

**Submitted to:  
House Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies**

**Submitted by:  
Kimberly D. Acquaviva, PhD, MSW  
The Friends of the National Institute on Aging, Chair**

May 1, 2009

Chairman Obey and members of the Subcommittee, thank you for the opportunity to provide testimony regarding the crucial role of the National Institute on Aging (NIA) within the National Institutes of Health (NIH) and the need for increased appropriations to ensure sustained, long-term growth in aging research in the Fiscal Year 2010 budget and beyond.

The Friends of the NIA is a coalition of 50 academic, patient-centered and not-for-profit organizations that conduct, fund or advocate for scientific endeavors to improve the health and quality of life for Americans as we age. As a coalition, we support the continuation and expansion of NIA research activities and seek to raise awareness about important scientific progress in the area of aging research currently guided by the Institute.

My testimony today highlights the relevance of the work of the NIA to each and every American, as well as opportunities for future progress that are dependent on Congressional action to build upon the unprecedented \$10.4 billion in the American Recovery and Reinvestment Act (ARRA) for NIH research and training activities in Fiscal Year 2010.

**The Relevance of the Work of the NIA**

Because the NIA leads the Federal effort on aging research, it is easy to assume that the work of the Institute primarily benefits older adults. While the work of the NIA has a clear benefit to older adults, NIA touches the lives of every American – from 3-year-old children to 103-year-old older adults. Each one of us benefits from NIA-supported scientific research to unlock the secrets of aging so that we can extend the healthy, active years of our lives.

The National Institute on Aging (NIA) leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults. NIA's mission is three-fold: (1) Support and conduct genetic, biological, clinical, behavioral, social, and economic research related to the aging process, diseases and conditions associated with aging, and other special problems and needs of older Americans; (2) Foster the development of research- and clinician-scientists for research on aging; and (3) Communicate information about aging and advances in research on aging with the scientific community, health care providers, and the public. The NIA carries out this mission by supporting both extramural research at universities and medical centers across the United States and vibrant intramural research at the NIA's laboratories in Baltimore and Bethesda, Maryland.

I could provide the Subcommittee with pages of facts and figures about the number of older adults in the US, the rising costs of health care, and the incidence and prevalence of debilitating age-related disorders. I could outline the business case for the need for increased NIA funding, citing current statistics demonstrating the financial cost of Alzheimer's Disease and other diseases and conditions of aging to Medicare, Medicaid, and employer-funded insurance plans each year in America. I could make the case for increased NIA funding by pointing to reams of data demonstrating that as a nation, we are woefully unprepared to meet the needs of aging Baby Boomers. As a coalition, The Friends of the NIA has provided testimony filled with these kinds of statistics in years past, but those statistics failed to serve as a compelling call to action with regard to our nation's investment in aging research. This is not to say that these statistics are unimportant. Numbers matter – for example, knowing that there are 5.3 million Americans living with Alzheimer's Disease today is important because it gives us a quantifiable means of measuring the scope of a problem, particularly when we look at changes in that number over time. But numbers fail to tell the whole story.

Citing statistics about the number of people affected by aging-related diseases and conditions sometimes has the unintended effect of making the magnitude of the problem seem incomprehensibly huge and by extension, insurmountable to solve. The picture that numbers paint is often a lot like an aerial photograph of a crowded football stadium. You get a general sense of the size of the crowd, but the resolution is poor when it comes to seeing the details on any of the faces.

It is difficult to conceptualize what “over five million people with Alzheimer's Disease” really *means* on a personal level. Five million is a staggeringly large number, monolithic in its mass and concomitant anonymity. It is much easier for me to wrap my brain around the concept of *one* person with Alzheimer's Disease. A former labor and delivery nurse with an encyclopedic memory of family history, my grandmother used to sit at the kitchen table with me and tell me the story behind each of the old family photos I unearthed from the steamer trunk up in her dusty attic. I remember what it felt like when I became a stranger to her. And I remember how frightened Grandma looked over the years as she watched her treasured memories slip out of her grasp and drift away like dandelions on the wind.

As you consider my testimony today, a group of Americans – the size of which exceeds the population of several States – is living with the same disease my grandmother had. Alzheimer's Disease is just one of several diseases and conditions of aging whose mysteries NIA is working tirelessly to solve. For each person living today with Alzheimer's Disease or Parkinson's Disease or Amyotrophic Lateral Sclerosis, there are countless family members, friends, and neighbors whose lives have been touched by the disease as well. We must also remember the countless hours of care and financial resources (both public and private) devoted to addressing the needs of individuals living with these diseases.

#### **The Challenges and Opportunities Ahead**

Today, millions of people are facing the loss of their functional abilities, their independence, and their lives to diseases like Parkinson's Disease, Amyotrophic Lateral Sclerosis, Frontotemporal Dementia, and Alzheimer's Disease. The numbers are staggering, to be sure.

But behind the numbers are the individual people they represent: the woman from your home district who is juggling work responsibilities while struggling to provide care for her husband, a proud man diagnosed a year ago with Amyotrophic Lateral Sclerosis (ALS). Or the 45-year-old father of two, recently diagnosed with early onset Alzheimer's Disease and struggling to find the right answer to his young son's question of "Daddy, why?"

There is a pressing need for increased funding for the NIA to advance research on Alzheimer's Disease not simply because over 5 million people are living with the disease today, but also because we do not yet know how to prevent someone else from developing Alzheimer's Disease tomorrow - and we cannot cure them if they do. We do not yet know how to prevent our spouses from developing ALS tomorrow, and we cannot cure them if they do. We do not yet know how to prevent our adult children from developing Parkinson's tomorrow, and we cannot cure them if they do. The urgent need for NIA-supported researchers to solve the mysteries surrounding these and other diseases of aging stems not only from the fact that millions of people are suffering from particular diseases today but also from the recognition that without a sustained investment in aging research, we will remain powerless to stop these diseases from striking our parents, our spouses, our children, our neighbors, our friends, and our communities tomorrow.

Today, in every community, on every block, and in every family in America, diseases and conditions of aging cause pain, suffering, and impairment among older adults. This is our reality today. But this does not have to be our reality tomorrow.

Chairman Obey and members of the Subcommittee, the power rests with you and your fellow members of Congress to change the course of human history with regard to how we age in America. This is in no way an overstatement of the significance of your role in the scientific discovery process. When Congress took action to provide an unprecedented \$10.4 billion for the NIH in the American Recovery and Reinvestment Act (ARRA), the immediate impact was like putting a quarter tank of gas into a high-performance racecar that had previously been running on fumes - finally, there was enough fuel to support rapid acceleration and increased forward momentum.

Between FY 2003 and FY 2009, scientists saw a series of nominal increases and cuts that amounted to flat funding for NIH and a 12.9% reduction in constant dollars for the NIA. This meant that for the past six years, not only was the NIA racecar running on fumes, it was sliding backwards downhill. No matter how fast a racecar has the potential to be, no matter how skillful its driver, and no matter how talented its pit crew, a racecar cannot go anywhere without fuel. Because of the infusion of fuel provided to the NIH by Congress in the American Recovery and Reinvestment Act, the NIA racecar is moving forward and is poised to continue rapidly accelerating towards the scientific discoveries that we as a nation are counting on the NIA to achieve. In the NIA, America has a high-performance race car and a team of the world's best drivers, highly capable of tackling the toughest race tracks out there - Alzheimer's Disease, Parkinson's, Heart Disease, Frontotemporal Dementia, and Amyotrophic Lateral Sclerosis, among others. Biomedical and behavioral research requires a sustained investment, much like winning a race requires sufficient gas to make it to the finish line. Congress holds in its hands the fuel we need to ensure our collective victory as a nation in the race to conquer diseases and conditions of aging.

NIH is the primary funder of biomedical research in this country and as such, NIA leads the Federal effort to advance biomedical and behavioral research in aging. We do not yet have the knowledge needed to predict, preempt, and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have the knowledge needed about disease processes to understand how best to prevent, diagnose, and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships between biology, genetics, and behavioral and social factors related to aging. We do not yet have a sufficient pool of new investigators entering the field of aging research. Bold, visionary, and sustainable investments in the NIA will make it possible to achieve measurable gains in these areas sooner rather than later.

The member groups of the *Friends of the National Institute of Aging* respectfully urge this Subcommittee to provide sustained support for biomedical and behavioral research by increasing funding for NIA by a minimum of 7 percent in Fiscal Year 2010 to correspond with the overall funding increase to NIH. NIA and the health-enhancing and life-saving biomedical, behavioral and social research it supports require bold, visionary, and sustainable funding to succeed in transforming the health of our nation. Americans depend upon the NIA to facilitate the acceleration of discoveries to prevent, treat, and potentially cure a wide range of debilitating age-related diseases and conditions. NIA-supported scientists are poised to make breakthroughs in the prevention and treatment of a host of age-associated diseases and conditions, but in order to achieve these powerful results, meaningful investments in aging research must be made now.

While the Friends of the NIA recognizes that there is enormous competition for Congressional appropriations, we believe that an increase in funding for the NIH will yield unprecedented returns in terms of accelerating the rate of basic discovery and stimulating the rapid development of interventions with the potential to offer significant public health benefits for our aging population.

Mr. Chairman, the Friends of the NIA thanks you for this opportunity to outline the challenges and opportunities that lie ahead as you consider the FY 2010 appropriations for the NIH. We would be happy to furnish additional information upon request.

#### Contact Information

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## Friends of NIAAA

*Submitted by Tom Donaldson, President  
National Organization on Fetal Alcohol Syndrome  
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*Testimony on behalf of the **FRIENDS OF NIAAA**  
Regarding the Fiscal Year 2010 Appropriation  
for the **National Institute on Alcohol Abuse and Alcoholism**  
before the United States House of Representatives Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
May 1, 2009*

Mr. Chairman and Members of the Subcommittee:

The Friends of the National Institute on Alcohol Abuse and Alcoholism, a coalition of scientific and professional societies, patient groups, and other organizations committed to preventing and treating alcohol use disorders as well as understanding the causes and public health consequences of alcoholism and alcohol-related problems, is pleased to provide testimony in support of the NIAAA's extraordinary work. The coalition does not receive any federal funds.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is the lead Federal entity for biomedical and behavioral research focused on uncovering the causes and improving prevention and treatment of alcohol abuse, alcoholism and other health effects of alcohol. NIAAA funds 90 percent of all alcohol research in the United States. This research is designed to reduce the enormous health, social, and economic consequences caused by excessive drinking. Approximately 18 million Americans meet the criteria for a diagnosis of alcohol abuse or dependence (alcoholism), and 40 percent of Americans have direct family experience with alcohol abuse or dependence. Annually, 79,000 deaths are attributable to alcohol, and excessive alcohol consumption is the third leading preventable cause of death in the U.S.

Alcohol remains the most commonly abused drug by youth and adults alike in the United States. The financial burden from alcohol abuse and alcoholism on our nation is estimated at \$185 billion annually. More than 70 percent of the cost borne by society relates to the enormous losses to productivity due to alcohol related illnesses and the loss of earnings resulting from premature deaths. Up to 40 percent, or almost half, of patients in urban hospital beds are there for treatment of conditions caused or exacerbated by alcohol including diseases of the brain, liver, certain cancers, and trauma caused by accidents and violence.

Because of the critical importance of alcohol research for the health and economy of our nation, we write to you today to request your support for a **6.7 percent increase for NIAAA** in the Fiscal 2010 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. That would bring total funding for NIAAA in Fiscal 2010 to \$465,500,000. This work deserves continuing, strong support from Congress. Below is a list of key new NIAAA initiatives

that could be pursued with additional investment, and a short list of significant NIAAA accomplishments and successes.

New NIAAA initiatives:

- New technologies to advance identification of the genes likely to influence the risk for alcoholism, and advancing discovery of new behavioral treatments and medications development;
- Acquiring scientific expertise in the areas of novel biosensors for the measurement of alcohol, computational neurobiology of alcohol, and geomapping to improve policies surrounding alcohol prevention.
- Longitudinal studies to: expand our understanding of alcohol effects on the developing adolescent brain; determine how alcohol use affects development of co-morbid disorders and how other disorders affect the emergence and progression of alcohol use disorders;
- Acceleration of medications development for treatment of alcoholism. More specifically, the development of promising compounds to treat alcohol dependence, including compounds that reduce the number or duration of heavy drinking occasions, and those that can be used for individuals who are not abstinent at the start of treatment;
- Expanding research to understand how individuals change their harmful drinking behaviors either in the presence or absence of treatment;
- Efforts to accelerate discoveries on nerve cell networks and their application to clinical issues surrounding tolerance, physical dependence, physical withdrawal and relapse, by integrating the efforts and findings of investigators from various scientific fields and disciplines;
- Understanding the neural basis for the transition from drinking to compulsive drinking.

A partial list of important NIAAA advances:

***Gene identification informing medications development***

The Friends of NIAAA commends NIAAA for making significant progress in identifying genes that contribute to the development of alcohol dependence, and medications targeting molecules identified in these studies are now in preclinical and clinical testing. Moreover, pharmacogenetic studies have demonstrated that the effectiveness of medications varies among individuals, depending in part upon which variants of specific genes they carry. Information from these studies will enable health care providers to personalize the treatment they offer their patients.

***Gaining a better understanding of the full spectrum of alcohol dependence***

A recent study has given us new insight into the face of alcoholism in the U.S. While clinicians and researchers have long recognized the variation within the alcohol dependent population, the public perception of a 'typical alcoholic' remains that of a dysfunctional individual affected by the chronic relapsing subtype of the disorder. In fact, this subtype occurs in a relatively small percentage of the alcohol-dependent population. The Friends of NIAAA is pleased that recent analyses of data from NIAAA's National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) have identified distinct subtypes of alcohol dependence, and the coalition applauds NIAAA for maintaining the important survey. Because these analyses were performed on data representing the general population, and not specifically on data from people in alcohol treatment settings, they provide a much broader and more accurate picture of the range of individuals who suffer from alcohol dependence and the multi-faceted nature of their disorder.

Certain subtypes of alcoholics have emerged that were previously undetected, or at least significantly underestimated, because few individuals with these subtypes of alcohol disorder access treatment. For example, young adults rarely seek any kind of help for their drinking but comprise the largest group of alcoholics in this country. In addition, nearly 20 percent of alcoholics are highly functional and well-educated with good incomes and stable families; less than 1/5 of this group seeks treatment. Individuals in other subtypes, although variable in age and other characteristics, make up the more severe end of the spectrum. They are more likely to have other psychiatric disorders and other substance abuse problems, are more likely to seek treatment and therefore have been well characterized in treatment-focused studies. NIAAA is using this knowledge to help all groups along the spectrum -- from harmful drinking to chronic, relapsing dependence -- access the care they need.

***Expanding screening and brief intervention into primary care and beyond***

About 3 in 10 U.S. adults drink at levels that increase their risk for physical, mental health, and social problems. Of these heavy drinkers, about 1 in 4 currently has alcohol abuse or dependence. Although relatively common, these alcohol use disorders often go undetected in medical and mental health care settings. Therefore, NIAAA-supported research is promoting screening and brief intervention in venues other than specialty treatment facilities. The Friends of NIAAA is pleased at NIAAA's progress in this arena and encourages the expansion of screening, brief intervention and referral as a critical primary prevention initiative.

For example, despite the high burden of illness associated with alcohol abuse and dependence, screening and diagnosis of alcohol problems are not standard components of primary health care for most individuals. NIAAA's *Helping Patients Who Drink Too Much - A Clinician's Guide* is helping to change this by providing a user-friendly, research-based approach to screening, diagnosing and managing patients with heavy drinking and alcohol use disorders for both primary care and mental health providers. Alcohol screening is simplified to a single question about heavy drinking days. Whether the patient has an alcohol use disorder or is a heavy, at-risk drinker, the *Guide* offers streamlined, step-by-step guidance for conducting brief interventions and managing patient care. The updated *Guide* offers several new resources including online

training with CME/CE credits, support for medication-based therapy in non-specialty settings, a handout with strategies to help patients reduce or quit drinking, a dedicated Web page devoted to the *Guide* and supporting resources for clinicians and patients, and an updated PowerPoint presentation for educators and instructors.

To complement the *Clinician's Guide*, NIAAA is releasing a consumer-oriented product called *Rethinking Drinking* which physicians can recommend to their patients as part of screening and brief intervention, and which is also available to the public at large. *Rethinking Drinking* takes an individual through the process of examining his/her drinking pattern, comparing it to drinking patterns in the general population and to recommended guidelines, and also assessing whether drinking is currently causing any symptoms or problems. Excessive drinkers are encouraged to examine the pros and cons of change, and then to develop a change plan and monitor their progress. Especially in the web version, many tools are provided that result in a highly individualized experience, with concrete change plans and advice about how to cut down. Additional resources are identified for those requiring more intensive care. *Rethinking Drinking* offers a significant opportunity to disseminate widely guidelines about drinking and recommended limits. In addition to being disseminated in the health care system, it could be used in many other settings, such as social service agencies, schools and colleges, workplaces, criminal justice settings and pastoral counseling. Finally, it is available on the web thus offering universal access to state-of-the art change assistance.

#### ***Addressing underage drinking on many fronts***

Underage drinking is an enormous public health concern. Alcohol is the drug of choice among children and adolescents. Annually, about 5,000 youth under age 21 die from motor vehicle crashes, other unintentional injuries, and homicides and suicides that involve underage drinking. The Friends of NIAAA commends NIAAA for continuing to emphasize research, evaluation, and outreach efforts regarding underage drinking, using a developmental approach. Employing such a framework will make us more effective in preventing and reducing underage alcohol use and its associated problems.

In response to NIAAA findings of the high prevalence of alcohol dependence in young adults, the extensive binge drinking among adolescents, and the serious consequences that result, the Surgeon General issued a *Call to Action To Prevent and Reduce Underage Drinking*. This concise report offers a comprehensive view of underage drinking and its consequences within a developmental framework. NIAAA provided the scientific foundation for *the Call to Action*, a collaborative effort of the Office of the Surgeon General, NIAAA, and the Substance Abuse and Mental Health Services Administration.

Given the high rates of drinking (especially binge drinking) among adolescents, coincident with significant developmental changes in the brain and nervous system, it is critical to better understand the impact of alcohol exposure on the developing brain. NIAAA recently funded 2 research initiatives to address this issue. One initiative is aimed at increasing our understanding about the short- and long-term effects of child and adolescent alcohol consumption on the developing brain. Another initiative is focused on understanding the effects of alcohol and

pubertal hormones on brain development and on differences in drinking patterns and vulnerabilities between boys and girls. In addition, NIAAA is currently focusing on developing guidelines for screening children and adolescents for risk for alcohol use and alcohol use disorders.

***Advancing the understanding of the mechanisms and consequences of prenatal alcohol exposure***

Fetal Alcohol Spectrum Disorders (FASD) is the nation's leading known non-hereditary preventable cause of mental retardation and birth defects. The Friends of NIAAA commends the Institute for its continuing work in this field to define the full range of FASD/prenatal alcohol phenotypes and endophenotypes across the lifespan using advanced methods, technologies and applications – integrative biology/systems biology and database approaches. Progress is also being made in developing and validating biomarkers to assess the exposure and insult to the mother and the fetus, and in the analyses of pre- and postnatal nutritional, genetic, epigenetic and environmental factors to determine risk or protective factors and co-morbidities (e.g., diabetes, tobacco and other drugs) that may alter susceptibility and natural history of FASD. NIAAA is also studying the safety and efficacy of interventions (e.g., nutritional, pharmacological, neurobehavioral, and environmental) during periconceptional, pregnancy, and lactational periods, and elucidating the biological mechanisms that contribute to ethanol teratogenesis in a range of experimental models and in humans, including mechanistic links to biomarkers and treatment.

Thank you, Mr. Chairman, and the Subcommittee, for your support for the National Institute on Alcohol Abuse and Alcoholism

**Testimony Submitted for the Record  
U.S. House of Representatives  
House Appropriations Committee  
Labor-HHS Subcommittee  
Submitted on April 23, 2009**

**Submitted by  
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**Testimony Submitted for the Record  
U.S. House of Representatives  
House Appropriations Committee  
Submitted on April 23, 2009**

Goodwill Industries International, Inc. (GII) is North America's leading nonprofit provider of employment training, job placement services and other community programs for people who have a disability, lack education or job experience or are facing economic challenges. Goodwill programs strengthen communities and families and promote independence and dignity for people who need it most.

The roots of today's Goodwill Industries began as a simple idea in 1902 when Rev. Edgar Helms set out to help poor immigrants in Boston's South End by collecting clothes and household items from wealthier Bostonians to give clothing and household items for the struggling immigrants. He discovered, to his surprise, that the immigrants were too proud to simply accept the items. So he took his idea a step further by enlisting volunteers to repair, clean, and sell the items at reasonable prices. He used the revenue to provide wages to the workers – and the first Goodwill Industries store was born.

More than 100 years later, one of Goodwill Industries greatest strengths continues to be its entrepreneurial approach to sustaining its mission. In 2007, the Goodwill Industries network raised more than \$3 billion through its retail, contracts, and mission services operations. Nearly 84 percent of the funds Goodwill Industries raised in 2007 were used to serve more than 1 million different people, including more than 163,000 job placements. Considering that more than 5 million people have lost their job since the current recession started, Goodwill Industries' commitment is as strong as it has ever been to working with policymakers toward implementing solutions that will restore economic stability by empowering disadvantaged populations.

Especially during such trying economic times, Goodwill Industries understands the difficult challenge that appropriators face as they struggle to stretch limited resources to support an ever-increasing list of national priorities. While our agencies care about a host of federal funding streams, GII has identified the following funding priorities, and therefore urges Congress to provide adequate funding in FY 2010 for these critical programs that support the efforts of local Goodwill agencies across the country.

**Workforce Investment Act and Vocational Rehabilitation:** Of the more than 1 million people Goodwill Industries served in 2007, more than 180,000 people were referred to Goodwill Industries for employment services through the Workforce Investment Act (WIA) (17.6 percent of all served) and state Vocational Rehabilitation agencies (4.5 percent of all served). Goodwill Industries agencies operate one-stop centers to provide skills training, job placement and job retention services to people with disabilities, welfare recipients and other job seekers. Many local Goodwill Industries agencies are one-stop lead operators, or operators in association with other service providers, and are active on state and local workforce boards.

GII thanks the Subcommittee for including nearly \$4 billion for the workforce system in the recently enacted *American Recovery and Reinvestment Act of 2009 (ARRA)*. The \$4 billion infusion for the workforce system in the ARRA will significantly increase the

system's capacity to respond to the economic crisis. However, GII believes that the 40 percent cut in inflation-adjusted dollars to these programs during the previous Administration, as well as the FY 2008 WIA rescission, has left the workforce system vastly under-funded. Now is the time to reverse this trend.

Unemployment rates generally lag behind all other economic indicators after recovery from a recession, taking months or even years to return to previous levels. The current unemployment rate is now at 8.5 percent and is expected to worsen in the foreseeable future. With unemployment rates expected to remain high, adequate investments by the Subcommittee in FY 2010 for workforce programs will be vitally necessary if we are to help people impacted by the recession to quickly rejoin the labor force by ensuring access to quality employment services and job training opportunities.

Lack of funding for WIA also places a strain on mandatory partner programs, including Vocational Rehabilitation (VR), which are being asked to contribute more funding to pay for infrastructure and other costs associated with the operation of the one-stop centers. Meanwhile, the Public Vocational Rehabilitation program is already under-funded to meet the needs of its target populations.

***GII urges the Subcommittee to increase funding for WIA and VR to better address the tremendous increase in demand for services by jobseekers in this recession.***

**Senior Community Service Employment Program (SCSEP):** The Senior Community Service Employment Program (SCSEP) helps provide low-income older workers with community services employment and private sector job placements. Program participants provide vital services in their communities at locations such as food banks, libraries, schools, senior centers, and child care centers while learning critical skills that lead to unsubsidized placement in the community. The return on investment to communities is over 300 percent for every dollar invested in SCSEP, since SCSEP participants are paid the minimum wage, yet would cost communities more than \$17 per hour if hired for these activities.

During Program Year 2008 (July 1, 2007 through June 30, 2008), as one of the newest SCSEP grantees, GII has worked with the U.S. Department of Labor as a national intermediary to enroll or place 1,200 older workers in community service opportunities or jobs. These SCSEP participants contributed a total of 1,186,407 community service hours. In addition, more than 300 participants exited the program for employment, with an average starting wage of \$9.84.

According to an Urban Institute report (March 2009), the unemployment rate for older workers over 65 years old reached 6.8 percent in February 2009, the highest level since the federal government started tracking such trends in 1948. Congress recently demonstrated its strong support for older workers by 1) the allocating \$120 million for SCSEP in the ARRA, and 2) increasing FY 2009 funding for SCSEP by 10 percent to adjust for the latest installment of the minimum wage increase without having to reduce participant levels. GII is particularly grateful for the additional funding provided by the ARRA, but current SCSEP funding levels still can only provide enough services to assist one percent of the eligible population.



*In light of rising unemployment for older workers, as well as many retirees being forced to return to the workforce as a result of the recession, Goodwill urges the Subcommittee to increase SCSEP funding to ensure its ability to better meet the needs of the increasing number of low-income older workers.*

**Green Jobs:** GII believes that the green jobs sector has great potential for increasing employment opportunities in high-growth fields for people with employment barriers and many local Goodwill Industries agencies are helping workers learn skills that will help them secure jobs in energy efficiency and alternative energy industries. We greatly appreciated the Subcommittee's inclusion of \$500 million for sectoral initiatives focused on green related industries in ARRA and *encourage the Subcommittee to fully fund the Green Jobs Act in FY 2010 to direct additional resources toward sectoral initiatives that will provide employment opportunities in "green jobs."*

#### **Conclusion**

GII thanks you for considering our requests and we look forward to working with the Subcommittee on FY 2010 funding. As our nation faces an economic crisis that many experts believe to be the worst since the Great Depression, GII's network of 160 local Goodwill Industries agencies in the United States stands ready to leverage its existing infrastructure to supplement government programs that enhance the dignity and quality of life of individuals, families, and communities by eliminating barriers to opportunity and helping people in need to reach their fullest potential through the power of work. Federal investments are critical and GII urges you to provide adequate funding for the programs outlined in this testimony.

**Harlem United Community AIDS Center, Inc.**  
**Written Testimony to the House Labor-Health and Human Services**  
**Appropriations Subcommittee**  
**Regarding Fiscal Year 2010 HIV/AIDS Related Funding**  
**Submitted by: Patrick McGovern, CEO Harlem United Community AIDS Center, Inc.**  
**[pimcgovern@harlemunited.org](mailto:pimcgovern@harlemunited.org); (212) 803-2850**  
**May 1, 2009**

**Funding Request Overview**

Harlem United Community AIDS Center, Inc. (Harlem United) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2010 funding for HIV/AIDS related programs. Harlem United was founded in 1988 as a community-based, non-profit organization providing comprehensive, integrated care in a healthy and healing environment. We serve individuals and families living with HIV and AIDS in the greater Harlem and South Bronx neighborhoods of New York City. Touching the lives of more than 6,000 people each year through our programs, Harlem United offers its clients an array of evidence-based, outcomes-driven, culturally-sensitive medical and support services, including: primary health care and dental care; mental health and substance use counseling; individual psychotherapy and case management; and supportive housing.

For far too long, federal funding for domestic HIV/AIDS programs has been inadequate, leaving communities struggling to meet the prevention, care, and treatment needs of people at risk for and living with HIV/AIDS. Harlem United values working with policymakers at the local, state, and federal levels to advance policies and programs that support HIV prevention, care and treatment, thus improving the lives of those living with and at risk for HIV/AIDS. We respectfully request the Subcommittee provide the following allocations in Fiscal Year (FY) 2010 to promote HIV prevention and HIV related research and treatment innovations:

- \$1.570 billion for HIV Prevention and Surveillance at the Centers for Disease Control and Prevention (CDC) to help stem the tide of the nation's HIV/AIDS epidemic, particularly among individuals and communities of color.
- At least \$2.81 billion in overall funding for the Ryan White Program, including the AIDS Drug Assistance Program, to provide essential services for more than 530,000 uninsured and underinsured low-income individuals and families impacted by HIV/AIDS.
- A minimum of \$610 million for the Minority AIDS Initiative, which funds programs across eight federal agencies to address HIV infection-related disparities among racial and ethnic groups.
- At least \$34 billion for the National Institutes of Health, with \$3.35 billion allocated to HIV/AIDS research to help identify and deliver new therapies.

As you may know, a group of 29 Democratic Representatives have submitted a letter to the Subcommittee in support of a \$1.57 billion FY 2010 allocation for CDC HIV related prevention activities; this effort was spearheaded by Representative Tammy Baldwin.

*Harlem United Community AIDS Center, Inc.  
FY 2010 Written Testimony Submitted to the  
House LHHS Appropriations Subcommittee  
May 1, 2009*

### **Introduction and Overview**

Despite ongoing prevention efforts, approximately 56,300 new HIV infections occur each year, and an estimated 21 percent of infected individuals are unaware of their HIV status. Moreover, the Centers for Disease Control and Prevention (CDC) estimates that there are 430,000 people with HIV in the U.S., who are not currently receiving HIV related medical care. In 2004, the Institute of Medicine estimated that more than 50 percent of Americans living with HIV had no reliable access to the care they needed to stay alive. Evidence has shown that new infections have been driven in large part by (1) people who were unaware of their status and unwittingly transmitted the virus, and (2) individuals who were diagnosed, but who were not treatment eligible and who were engaging in risk behaviors.<sup>1</sup> Prevention programs, routine HIV testing and universal access to care are essential to stemming the tide of the HIV/AIDS epidemic nationwide.

To prevent the incidence of HIV and ensure that all people living with HIV/AIDS have access to comprehensive and quality care that they need and deserve, Harlem United advocates ongoing and significant federal funding for domestic HIV/AIDS programs.

### **Bolster CDC HIV Prevention and Surveillance Efforts**

The CDC estimates that there are more than 1.1 million people living with HIV/AIDS in the United States and an estimated 56,300 new infections occur each year. With these staggering statistics, it becomes clear that a sustained federal investment in and commitment to HIV/AIDS initiatives are essential to advancing efforts to prevent and treat HIV infections. However, over the past six years, as the number of people living with HIV/AIDS has increased, federal funding for HIV prevention programs at the CDC has decreased by 19.3 percent. In FY 2009, CDC HIV related prevention and surveillance programs were flat-funded after facing a \$3.5 million cut in FY 2008. Harlem United calls upon the Subcommittee to provide a specific allocation of \$1.57 billion, an increase of \$877 million, for HIV prevention efforts at the CDC.

The current body of knowledge and research surrounding HIV prevention provides evidence for effective interventions, yet the CDC and state and local public health departments do not always have the resources to implement them. With increased federal funding, gaps in resources and fiscal needs will be alleviated and prevention efforts can be scaled up. Specifically, additional funding will allow the CDC to expand HIV testing efforts and prevention outreach, particularly among high-risk populations and communities of color, where the epidemic is disproportionately concentrated. The CDC also would be able to assist state and local health departments fund prevention programs that go beyond just testing for HIV. Furthermore, additional funding would allow the CDC to continue to build the capacity of community-based organizations to implement evidenced-based interventions and provide technical assistance. Lastly, the CDC also would be able to improve HIV monitoring and surveillance activities to ensure that accurate data on the disease are captured.

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<sup>1</sup> Federal guidelines do not allow for treatment until an individual's viral load reaches 350 or lower.

*Harlem United Community AIDS Center, Inc.  
FY 2010 Written Testimony Submitted to the  
House LHHS Appropriations Subcommittee  
May 1, 2009*

**Preserve Access to HIV Treatment for Low-income Individuals through the Ryan White Program**

Each year, the Ryan White Program provides care and treatment to more than half a million low-income individuals living with HIV/AIDS. This program is vital to those who have no medical coverage or face coverage limits, as it steps in as the “payer of last resort”. While the Ryan White Program was initially implemented as an emergency measure, it has become an integral part of the nation’s response to HIV, providing treatment for individuals who would otherwise not have access to care.

The AIDS Drug Assistance Program (ADAP), a critical component of the Ryan White Program that exists under Part B, provides HIV medications to program participants and funds for purchasing health insurance for eligible participants and services that enhance drug treatment therapies.

Unfortunately, growing caseloads and costs of treatment have left current funding levels inadequate. As such, Harlem United calls upon the Subcommittee to allocate at least \$2.81 billion in overall funding for the Ryan White Program, including the AIDS Drug Assistance Program.

**Strengthen the Minority AIDS Initiative**

The HIV/AIDS epidemic in the U.S. has hit racial and ethnic minority communities hard. While only 12 percent of the U.S. population is African American, this racial group accounts for 49 percent of all new AIDS cases. Hispanics account for 19 percent of new AIDS diagnoses, yet comprise only 12 percent of the total U.S. population. Combined, minorities represent 71 percent of new AIDS cases, 67 percent of all people living with HIV/AIDS, and 70 percent of deaths caused by AIDS. These grim statistics demonstrate the critical need for the Minority AIDS Initiative (MAI).

MAI provides funding to community-based organizations and health care providers to implement prevention and treatment programs specifically tailored to racial and ethnic minority populations. The Initiative, designed to complement other HIV efforts, strengthens the capacity of organizations serving communities of color to implement culturally appropriate HIV prevention programs and treatment services, in order to reduce the incidence of HIV and improve HIV related health outcomes among these communities.

Given the urgent need to reduce HIV/AIDS disparities among racial and ethnic communities in the U.S., Harlem United urges the Subcommittee to allocate a minimum of \$610 million for the Minority AIDS Initiative.

*Harlem United Community AIDS Center, Inc.  
FY 2010 Written Testimony Submitted to the  
House LHHS Appropriations Subcommittee  
May 1, 2009*

#### **Enhance HIV Treatment and Therapeutics Research**

Despite breakthroughs in HIV treatment and prevention research, currently, no vaccine or cure exists for HIV/AIDS. With approximately, 56,300 new HIV cases each year, it is crucial that the U.S. increase its commitment to research aimed at the prevention and treatment of this disease.

The National Institutes of Health (NIH) is the global leader in AIDS research. It conducts research on drug therapies, vaccines and evidenced-based behavior and biomedical prevention interventions. Previous breakthroughs in NIH AIDS research include advances in antiretroviral therapy and drug regimens that have decreased HIV related morbidity and mortality and reduced the risk of mother-to-child transmission of HIV. While NIH research has significantly contributed to HIV prevention and treatment programs that have improved the quality-of-life for many, additional and on-going research is needed to advance existing HIV/AIDS treatments. Therefore, Harlem United calls upon the Subcommittee to allocate at least \$34 billion for the National Institutes of Health, with \$3.35 billion allocated to HIV/AIDS research

#### **Conclusion**

Harlem United maintains a strong commitment to working with Members of Congress, other community-based organizations, and stakeholders to curtail the HIV epidemic and ensure that individuals living with HIV/AIDS have access to quality care and treatment. By providing the FY 2010 funding levels detailed above, we believe the Subcommittee will be taking the necessary steps towards accomplishing the goals of HIV prevention and universal access to care, ensuring that this disease will no longer threaten our nation.



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***CAUSE FOR A CURE***

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STATEMENT  
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ON BEHALF OF THE  
HEPATITIS B FOUNDATION  
DOYLESTOWN, PA

PRESENTED  
TO THE  
UNITED STATES HOUSE OF REPRESENTATIVES  
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES

April 14, 2009

This testimony is being provided to highlight the urgent need to address the public health challenges of chronic hepatitis B by strengthening programs at the Centers for Disease Control and Prevention, and the National Institutes of Health.

Mr. Chairman, my name is Dr. Timothy Block, and I am the President and Co-Founder of the Hepatitis B Foundation and its research institute, the Institute for Hepatitis and Virus Research. I also serve as the President of the Pennsylvania Biotechnology Center and am a professor at Drexel University College of Medicine. My wife Joan, and I, and another couple, Paul and Janine Witte, from Pennsylvania started the Hepatitis B Foundation more than 18 years ago to find a cure for this serious chronic liver disease and provide information and support to those affected.

Thank you for giving the Hepatitis B Foundation (HBF) the opportunity to provide testimony to the Subcommittee as you begin to consider funding priorities for Fiscal Year (FY) 2010. We are grateful to the Members for their interest, and particularly Congressman Honda, who has provided consistent and strong leadership for efforts to control and find cures for hepatitis B.

Today, the HBF is the only national nonprofit organization solely dedicated to finding a cure and improving the lives of those affected by hepatitis B worldwide through research, education and patient advocacy. Our scientists focus on drug discovery for hepatitis B and liver cancer, and early detection markers for liver cancer. HBF staff manages a comprehensive website which receives almost one million visitors each year, a national patient conference and outreach services. HBF public health professionals conduct research initiatives to advance our mission.

The hepatitis B virus (HBV) is the world's major cause of liver cancer – and while other cancers are declining, liver cancer is the fastest growing in incidence in the U.S. Without intervention, as many as 100 million will die from a HBV-related liver disease, most notably liver cancer. In the U.S., up to 2 million Americans have been chronically infected and more than 5,000 people die each year from complications due to HBV.

Most people were infected with HBV from their mothers at birth, and most people who are infected are unaware of their infection. Even for people infected at birth, illness, when it occurs, usually does not appear until decades later when the individual is in their prime at age 30-50 years. Additionally, although all ethnic groups are affected, it disproportionately affects Asians and Africans. Nearly 1 in 10 Asian Americans are chronically infected with hepatitis B.

But, the news is not all grim. There have been tremendous advances in research and in the control and treatment of hepatitis B over the past 30 years. There is a vaccine to prevent HBV infection. More vaccine research is needed, however, as there are growing questions as to how long lasting the vaccine protection is, if given in infancy. Unfortunately, for the nearly 400 million people already infected worldwide, the vaccine is too late.

For those already infected, there are now several medications that can be taken to control viral replication and prevent disease progression to end-stage liver disease and/or liver cancer, thereby reducing mortality and the need for liver transplantation. However, most cases of cirrhosis or liver cancer are diagnosed in the late stages, and current methods to treat liver cancer are in the dark ages. Early diagnosis of liver disease is also primitive. HBV screening as part of liver cancer

prevention and detection is thought to be one of the best hopes for effective management. We were getting close to solutions but lack of sustained support for public health measures and scientific research is threatening progress. The frightening increase in the number of HBV outbreaks this past year, and the growing incidence of liver cancer, while most other cancer rates are on the decline, represent examples of serious shortcomings in our system. In the U.S., 20,000 babies are born to mothers infected with HBV each year, and as many as 1,200 newborns will be chronically infected with the hepatitis B virus. More needs to be done to prevent new infections.

Mr. Chairman, as you know the two federal agencies that are critical to the effort to help people concerned with hepatitis B are: the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH).

#### **THE CENTERS FOR DISEASE CONTROL, DIVISION OF VIRAL HEPATITIS**

CDC's Division of Viral Hepatitis (DVH), the centerpiece of the federal response to controlling, reducing and preventing the suffering and deaths resulting from viral hepatitis, is chronically underfunded. DVH is included in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis.

While progress has been made in decreasing new infections, little has been done about chronic hepatitis B and C, which impacts more than 6 million Americans and if left untreated, often leads to fatal liver failure or liver cancer. DVH - currently funded at \$17.5 million - would need an annual funding level of at least \$40 million to restore its funding level, adjusted for inflation, to the funding level it received in FY 2003. The HBF urges a FY 2010 funding level for the Division of Viral Hepatitis of \$40 million.

Despite the availability of a safe and effective vaccine, there continues to be almost 100,000 new HBV infections each year with the greatest incidence among young adults between 19-49 years. Also alarming is the fact that up to 75% of Americans infected with HBV are unaware of their status. In addition, as many as one-third of persons infected with HIV are co-infected with HCV. Even more disturbing, chronic viral hepatitis is the leading cause of liver transplantation and liver cancer, which is one of the fastest growing cancers in incidence in the U.S. while most other cancers are on the decline. A strong, well funded CDC, in particular the DVH is the country's best hope to manage the critical public health problem of chronic viral hepatitis.

If adequate funds were provided to DVH to improve surveillance, screening, and early intervention, there would be a measurable impact on reducing ongoing transmission, disease progression and the ethnic health disparities associated with chronic HBV/HCV and liver cancer. Our nation needs a healthy and productive population to meet the challenges of the future, and rebound from these difficult times. An investment in public health will put us on a preferred path of prevention and wellness.



## THE NATIONAL INSITUATES OF HEALTH

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with hepatitis B and liver cancer. The Hepatitis B Foundation joins with the Ad Hoc Group for Biomedical Research and requests an increase of at least 7% for the National Institutes of Health in FY 2010

We commend the Committee for including substantial funding for the National Institutes of Health in the American Recovery & Reinvestment Act (ARRA). This funding will provide immediate funding to improve the length and the quality of the lives of our citizens, while at the same time stimulating the economy. We also want to thank the Committee for the \$938 million increase included for NIH in the FY 2009 Omnibus Appropriations Act. This additional funding is an important step toward regaining the potential that has been lost in the last several years when funding has not kept pace with the costs of conducting biomedical research. Promising research has not been funded, clinical trials have been delayed or terminated, and young investigators have started to pursue alternative careers. The increases in last year's appropriations and the ARRA package will start to change this. An increase of at least 7% in FY 2010 is critical to maintain the momentum

In FY 2008, NIH spent approximately \$53 million on hepatitis B funding overall. An additional \$40 million per year could make transformational advances in research leading to better treatments for HBV. The HBF recommends that an additional \$40 million be allocated for HBV research in FY 2010 and that overall NIH be increased by at least 7%.

Mr. Chairman, I would like to take this opportunity to commend the leadership of NIH, and especially the leadership of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Cancer Institute, and the National Institute of Allergy and Infectious Diseases for their continued interest in liver disease research. They have performed admirably with the limited resources they are provided; however, more is needed.

The NIH published a 10-year Liver Disease Research Action Plan in 2004, and to date, NIDDK has succeeded in several important areas such as funding a network of HBV Clinical Research Centers and hosting the first HBV Consensus Conference focused on identifying best treatment practices for chronic hepatitis B infections. With an increase of \$40 million in FY 2010 funding for HBV research, we believe that transformational progress can be made.

## SUMMARY AND CONCLUSION

While the HBF recognizes the demands on our nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify higher funding levels for the CDC's Division of Viral Hepatitis and the National Institutes of Health.

Significant progress has been made in developing better treatments and cures for the diseases that affect humankind due to your leadership and the leadership of your colleagues on this Subcommittee. Significant progress has also similarly been made in the fight against hepatitis B. In conclusion, we specifically request the following funding for FY 2010 programs:

- Fund the CDC's Division of Viral Hepatitis at \$40 million - to restore its funding level, adjusted for inflation, to the funding level it received in FY 2003 - to strengthen the public health response to chronic viral hepatitis; and
- Provide at least a 7% increase over FY 2009 for the NIH, including a \$40 million increase per year for hepatitis B research.

The Hepatitis B Foundation appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

Thank you.

Colin Schwartz  
 HCAP Coordinator, Associate, Viral Hepatitis/Government Relations  
 Hepatitis C Appropriations Partnership, National Alliance of State & Territorial AIDS Directors  
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The Hepatitis C Appropriations Partnership (HCAP) was formed in June 2004 as a coalition of hepatitis C community-based organizations, public health and provider associations, national HIV and HCV organizations, and members of the diagnostics and pharmaceutical industry. We work with policy makers and public health officials to increase federal support for hepatitis B and C prevention, testing, education, research, and treatment.

As you craft the FY2010 Labor-HHS-Education Appropriations legislation, we urge you to consider the following critical funding needs of HIV/AIDS, viral hepatitis, and STD programs:

- \$50 million for CDC's Viral Hepatitis Prevention Program, including a doubling of resources for the Adult Viral Hepatitis Prevention Coordinator Program to \$10 million.
- \$16 million for hepatitis B vaccination for high-risk adults through the Section 317 Vaccine Program;

#### Viral Hepatitis Prevention Programs

HCAP respectfully requests an increase of \$36.4 million for a total of **\$50 million** in FY2010 for the CDC's Division of Viral Hepatitis (DVH) to enable state and local health departments to provide basic core public health services. DVH currently receives \$18.3 million to address chronic viral hepatitis B and C impacting 6.2 million Americans. This is \$7 million less than its peak funding of \$25 million in FY2001. Currently CDC addresses viral hepatitis on outbreak at a time, which is neither cost-effective nor real prevention.

Of the DVH funding, \$5.2 million is used to fund the Adult Viral Hepatitis Coordinator Program with an average award to states of \$90,000. Doubling this program to \$10 million would allow states to implement a hepatitis prevention strategy. The coordinator position receives precious little above personnel costs, leaving little to no money for the provision of public health services including public education, hepatitis counseling, testing, and hepatitis A and B vaccine. In addition, there are no funds for surveillance of chronic viral hepatitis, which would allow states to better target their limited resources. Given the recent hepatitis public health crises in Nevada and New York, the government has a choice - invest in prevention now or wait until public systems are overwhelmed by a lack of infrastructure to address future outbreaks.

The greatest remaining challenge for hepatitis A and B prevention is the vaccination of high-risk adults. High-risk adults account for more than 75 percent of all new cases of hepatitis B infection each year and annually result in an estimated \$658 million in medical costs and lost wages. In FY2007, CDC allowed states to use \$20 million of 317 Vaccine funds to vaccinate high risk adults for hepatitis B and \$16 million in FY2008. By targeting high-risk adults, including those with hepatitis C, for vaccination, the gap between children and adults who have not benefited from routine childhood immunization programs can be bridged. HCAP requests a continuation of the **\$16 million** in Section 317 Vaccine funds in FY2010 for hepatitis B vaccination for high-risk adults with the request that in the future DVH receives dedicated funding for hepatitis A and B vaccine for high risk adults and funding to support the infrastructure necessary for vaccine delivery.

***Testimony Submitted for the Record to the Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies for  
FY 2010 Appropriations for HIV/AIDS Programs  
Submitted by the HIV Medicine Association  
Arlene Bardeguez, MD, MPH, Chair  
bardegad@umdnj.edu  
May 1, 2009***

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 3,600 physicians, scientists and other health care professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS throughout the U.S., lead HIV prevention programs and conduct research to develop effective HIV prevention and treatment options. As medical providers and researchers dedicated to the field of HIV medicine, we work in communities across the country and around the globe. We appreciate the fiscal challenges that you currently face, but the state of the economy makes it imperative that our nation has a strong health care safety-net, effective programs for preventing infectious diseases like HIV and a vibrant scientific research agenda.

The U.S. investment in HIV/AIDS programs has revolutionized HIV care globally making HIV treatment one of the most effective medical interventions available. A robust research agenda and rapid public health implementation of scientific findings have transformed the HIV epidemic reducing morbidity and mortality due to HIV disease by nearly 80 percent in the U.S. The Ryan White program has played a critical role in ensuring that many low income people with HIV have access to lifesaving HIV treatment. However, the impact of our diminished investment in public health and research programs over the last several years has taken its toll in communities across the country. HIV clinics are cutting hours and services while new HIV cases are increasing by at least 15 percent.

We face a critical juncture when we must either shore up our health care safety net, public health infrastructure and research programs or risk serious regression in our fight against this deadly disease. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP) a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to sustain and strengthen our investment in combatting HIV disease.

**Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)**

HIVMA strongly supports an increase of **\$1.27 billion in funding for the CDC's NCHHSTP** with an increase of **\$878 million for HIV prevention and surveillance**, an increase of **\$31.7 million for viral hepatitis** and **\$66.1 million for Tuberculosis prevention**.

Every nine and a half minutes a new HIV infection happens in the U.S. with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. While new HIV cases have increased, the CDC's HIV prevention budget has declined 19 percent compared to inflation since 2002. A failure to invest now in HIV prevention will be costly. The CDC estimates that the 56,300 new HIV infections each year in the U.S. may result in \$56 billion in medical care and lost productivity.

We strongly support the CDC initiative to integrate HIV screening into medical care and remain seriously concerned about the lack of federal resources available to state health departments, medical institutions, community health centers and other community based organizations for implementing these programs. Increased HIV screening with linkage to care and treatments will help lower HIV incidence and prevalence in the U.S. Effective treatment reduces the virus to very low levels in the body and greatly reduces the risk of HIV transmission. Furthermore through education, counseling and treatment, individuals who are aware that they have HIV are less likely to transmit the virus. The transmission rates among people who know their status is 1.7 percent to 2.4 percent compared to transmission rates of 8.8 percent to 10.8 percent for those who are unaware they are infected with HIV.

Despite the known benefit of effective treatment, 21 percent of people living with HIV in the U.S. are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within one year of diagnosis. Identifying people with HIV earlier through routine HIV testing and linking them to HIV care saves lives and is more cost effective for the health care system. One study found that people living with HIV disease receiving care at the later stages of the disease expended 2.6 times more in health care dollars than those receiving treatment according to the standard of care recommended in the federal HIV treatment guidelines.

An infusion of HIV prevention funding is critical to restore and enhance HIV prevention cooperative agreements with state and local health departments; to optimize core surveillance cooperative agreements with health departments and to expand HIV testing in key health care venues by funding testing infrastructure, the purchase of approved testing devices, including rapid HIV tests and confirmatory testing.

Finally, we also must increase support for science-based, comprehensive sex education programs. We strongly urge Congress to discontinue funding for unproven abstinence-only sex education programs and shift these funds to support comprehensive, age-appropriate sex education programs.

#### **CDC-Tuberculosis**

Tuberculosis is the major cause of AIDS-related mortality worldwide. Congress passed landmark legislation—the Comprehensive Tuberculosis Elimination Act of 2008—Public Law 110-873 last year that authorizes a number of actions that will shore up state TB control programs, enhance US capacity to deal with the serious threat of drug-resistant tuberculosis and escalate our efforts to develop urgently needed new “tools” in the form of drugs, diagnostics and vaccines. It is critical that the **\$210 million in funding authorized for FY 2010** in this important new law is appropriated for the CDC Division of TB Elimination. This represents an increase of \$66.1 million over current funding levels. Funding to support the prevention, control and elimination of tuberculosis must increase substantially if we are going to make headway against this deadly disease and to address the emerging threat of highly drug resistant tuberculosis.

#### **CDC-Viral Hepatitis**

Funds are urgently needed to provide core public health services and to track chronic cases of hepatitis. Hepatitis is a serious co-infection for nearly one-third of our HIV patients. We strongly urge you to boost funding the public health capacity for viral hepatitis programs and **increase funding for viral hepatitis at the CDC by \$31 million for a total funding of \$50 million.**

#### HIV/AIDS Bureau of the Health Resources and Services Administration

**We strongly urge you to increase funding for the Ryan White program by \$577 million in fiscal year 2010 with at least an increase of \$68.4 million for Part C for a total appropriation of \$270,254,000.**

Ryan White Part C funds comprehensive HIV care and treatment—the services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. While the patient load in Part C programs has been rising in number, funding for Part C has effectively decreased. Part C programs expect a continued increase in patients due to higher diagnosis rates and declining insurance coverage. During this economic downturn people with HIV across the country will rely on Part C comprehensive services more than ever. An increase in funding is critical to ensure that clinics are able to prevent staffing cuts, as well as, to ensure the public health of our communities. Part C of the Ryan White program has been under-funded for years, but new pressures are creating a crisis in communities across the country. The HIV medical clinics funded through Part C have been in dire need of increased funding for years. Years of near flat funding, combined with large increases in the patient population, are negatively impacting the ability of Part C providers to serve their patients.

With the rapid cost increases in all aspects of health care delivery, despite small funding increases, programs are still operating at a funding deficit because they are serving more patients than ever. In 2008, Part C programs will treat an estimated 248,070 – a dramatic 30% increase in less than 10 years. Part C clinics are laying off staff, discontinuing critical services such as laboratory monitoring, creating waitlists, and operating on a 4-day work week just to get by. HIVMA strongly supports the effort led by the Ryan White Medical Providers Coalition to **double funding for Ryan White Part C programs by Fiscal Year 2012**. These funds are urgently critical to meet the needs of HIV patients served by Part C around the country.

**We also respectfully urge you to include at least \$1 million in this year's Labor-HHS-Education appropriations bill for a study to evaluate the capacity of the HIV medical workforce as well as potential strategies to increase the numbers of young physicians, nurse practitioners and physician assistants entering HIV medicine.** More than a quarter century into the HIV epidemic, we are seeing the graying of our nation's HIV clinical workforce, and we have serious concerns about ensuring a new generation of HIV medical providers to care for Americans with HIV. We increasingly hear about HIV care coverage gaps and clinical programs with challenges in hiring and retaining medical staff. We must promptly and swiftly address this issue before its effects are felt in increases in morbidity and mortality from HIV.

#### National Institutes of Health (NIH) – Office of AIDS Research

**HIVMA strongly supports an increase of at least \$3.7 billion for all research programs at the NIH, including at least a \$500 million increase for the NIH Office of AIDS. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of Americans.**

HIVMA strongly supported the infusion of NIH research dollars included in the economic recovery bill. The desperately needed funding came at a critical time to sustain our nation's scientific research capacity while stimulating the economy in communities across the country.

Prior to the boost in NIH funding, the declining US investment in biomedical research had taken its toll in deep cuts to clinical trials networks and significant reductions in the numbers of high quality, investigator-initiated grants that were approved. With only one in four research applications receiving funding, the pipeline for critical discoveries and HIV scientists has been dwindling and our role as a leader in biomedical research is at serious risk.

Our past investment in a comprehensive portfolio was responsible for the dramatic gains that we made in our HIV knowledge base, gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. Gains that also helped us to reduce the mother to child HIV transmission rate from 25 percent to nearly 1 percent in the U.S. and to very low levels in other countries where treatment is available.

A continued robust AIDS research portfolio is essential to sustain and to accelerate our progress in offering more effective prevention technologies; developing new and less toxic treatments; and supporting the basic research necessary to continue our work developing a vaccine that may end the deadliest pandemic in human history. The sheer magnitude of the number of people affected by HIV— more than one million people in the U.S.; more than 33 million people globally – demands a continued investment in AIDS research if we are going to truly eradicate this devastating disease. We believe a high priority should be research to discover novel prevention strategies, to improve available treatment strategies to aid prevention and to maximize the benefits of antiretroviral therapy, especially in the populations disproportionately affected by HIV in the U.S. and in resource-limited settings.

We also continue to support the NIH's Fogarty International Center (FIC) and recommend an expansion of its programs and funding. The FIC training programs play a critical role in developing self-sustaining health care infrastructures in resource-limited countries. These important programs offer invaluable training and mentoring to indigenous physicians from the countries hardest hit by the HIV pandemic and other deadly infectious diseases, such as malaria and tuberculosis. Physicians trained through the FIC are able to develop research programs that more effectively address the health care, cultural and resource needs of their country's residents while also fostering the development of ongoing, robust research and clinical programs.

**Historically, our nation has made significant strides in responding to the HIV pandemic here at home and around the world, but we have lost ground in recent years, particularly domestically, as funding priorities have shifted away from public health and research programs. We appreciate the many difficult decisions that Congress faces this year but urge you to recognize the importance of investing in HIV prevention, treatment and research now to avoid the much higher cost that individuals, communities and broader society will incur if we fail to sustain these programs now. We have the opportunity to limit the toll of this deadly infectious disease on our planet and to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe.**



Written Testimony of Evelyn McKnight, AuD  
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Submitted May 1, 2009 to the United States House Committee  
 on Appropriations Subcommittee on Labor, Health &  
 Human Services, Education, and Related Agencies  
 The Honorable David Obey, Chairman

Mr. Chairman and Members of the Subcommittee:

As President and Co-Founder of Hepatitis Outbreaks National Organization for Reform (HONOREform), I want to take this opportunity to thank you for the leadership role this Subcommittee has played on healthcare acquired infections (HAIs). HONOREform is a non-profit foundation that advances the lessons learned in hepatitis outbreaks and seeks to prevent future healthcare-associated hepatitis epidemics through education and policy reform.

The Centers for Disease Control and Prevention (CDC) estimates there are 1.7 million infections resulting in approximately 99,000 deaths annually in the United States, making HAIs the fourth leading cause of death. Beyond the human toll, there is an enormous financial burden to our healthcare system.

We are deeply concerned with the rise in the number of disease outbreaks related to the reuse of syringes and misuse of multidose vials in the outpatient setting. In the January 2009 edition of the *Annals of Internal Medicine*, an article by the CDC, revealed the occurrence of 33 outbreaks of viral hepatitis in healthcare settings over the last decade. All of these documented outbreaks occurred in non-hospital settings and involved failure on the part of healthcare providers to adhere to basic infection control practices, most notably by reusing syringes and other equipment intended for single use.

I am a victim of what was the largest single source outbreak of Hepatitis C in U.S. history, until last year's Las Vegas, Nevada outbreak that potentially exposed over 63,000 patients to hepatitis C. In 2001, I contracted hepatitis C through an oncology clinic (non-hospital setting), in Fremont, Nebraska as I was fighting to survive breast cancer for the second time. 98 other patients from the oncology clinic became infected with hepatitis C. The nurse would reuse the syringe for port flushes, which would then contaminate a 500cc saline bag. The saline bag was used for other patients, which in turn became the source of infection for multiple cancer patients. This improper practice was repeated on a regular basis over a 2-



year period.

I utilized my malpractice settlement to establish HONORReform in 2007 to put an end to these completely preventable outbreaks. Over 100,000 patients seeking healthcare and treatment have received letters notifying them of potential exposure to hepatitis and HIV due to improper injection practices in the last ten years. In April 2009, two outbreaks in New Jersey, a cancer clinic and hospital, and an outbreak at a South Dakota-outpatient urology clinic, conducted large patient notifications which further illustrates that this problem requires immediate action to protect the citizens that are accessing our healthcare system each day.

Moreover, these hepatitis outbreaks are entirely preventable when healthcare providers adhere to proper infection control procedures. A 2002 study by the American Association of Nurse Anesthetists (AANA) found that 1% of practitioners felt it was acceptable to reuse a syringe for multiple patients and over 30% of healthcare providers believed it was acceptable to reuse a syringe on the same patient if the needle is changed. Mr. Chairman, beyond the significant risk posed to the physical health of patients, even the receipt of a notification of potential exposure can cause significant mental anguish and lead to an even greater danger – a loss of faith in the medical system by the public. Victims feel that they have been personally violated and betrayed by those to whom they entrusted their health. We, as a nation, can not afford to ignore the issue and hope it goes away.

Through its foundation, HONORReform has joined forces with the Accreditation Association for Ambulatory Health Care (AAAHC), American Association of Nurse Anesthetists (AANA), Association for Professionals in Infection Control and Epidemiology (APIC), Ambulatory Surgery Foundation (ASF), Becton, Dickinson and Company (BD), CDC, CDC Foundation, Nebraska Medical Association (NMA), and the Nevada State Medical Association (NSMA), to establish the One & One Campaign. The One & Only Campaign is an effort aimed at reeducating healthcare providers that syringes and other medical equipment must not be reused and empowering patients to ask the right questions when seeking healthcare. If patients are knowledgeable about injection safety, they will be empowered to speak up in their provider's office to ask if they are getting "*One Needle, One Syringe, and Only One Time*."

In fiscal year (FY) 2009, the CDC received \$2.5 million to establish a pilot campaign in Nevada for the launch of the One & Only Campaign, which we hope will be expanded to the national campaign with your support for continued and expanded funding in FY 2010. Each of these requests will have a profound impact on all patients and consumers. They are aimed at reducing the knowledge gap for providers, empowering patients, tracking HAIs to limit the spread of disease, and improving the quality and standards of care in our nation's ambulatory care facilities. By focusing on prevention, this committee can realize savings for healthcare systems and promote increased patient safety for all Americans.

Mr. Chairman, we respectfully request that the Subcommittee continue supporting prevention efforts at CDC, HHS and AHRQ to help prevent future hepatitis and HIV outbreaks through the following FY 2010 appropriations requests:

**HONORReform requests \$26 million for CDC's Division of Healthcare Quality and**

**Promotion** to build infrastructure for complete and consistent adherence to *injection safety and infection control guidelines in the delivery of outpatient care*.

As you know, the migration of healthcare delivery from primarily acute care hospitals to other non-hospital settings (e.g., home care, ambulatory care, free-standing specialty care sites, long-term care) requires that common principles of infection control practice be applied to the spectrum of healthcare delivery settings. The CDC needs additional resources to use the knowledge gained through these activities to detect infections and develop new strategies to prevent healthcare-associated transmission of blood borne pathogens. This request includes the following elements:

- *Provider Education and Awareness* - \$9 million be used to support CDC's efforts around provider education and patient awareness activities. Currently, the CDC along with patient advocacy organizations, foundations, provider associations and societies and industry partners have established the Safe Injection Practices Coalition. The requested funding would be used to roll out a national public health campaign focused on safe injection practices. Additionally, funds will be used to develop and disseminate safe practice materials and develop related tools designed for inpatient and outpatient settings. Innovative tools will be developed in conjunction with key partners and stakeholders for use by providers and healthcare personnel, including training tools to be used by professional organizations and accreditation and licensing groups to increase adherence to recommendations
- *Engineering and Innovation* - \$8 million would be used to support CDC in promoting private-sector healthcare solutions to injection safety and infection control problems by engage and incentivizing the private sector to innovate and create fast track engineering-solutions to injection safety and infection control problems through the development of innovative products to reduce infection transmission for inpatient and outpatient healthcare settings. With this funding, CDC will convene a roundtable with industry, conduct a study on available technology, assess opportunities for investment in research and development, and examine incentives required for adoption of equipment designed with engineering controls (e.g., sharps disposal containers, self-sheathing needles, safer medical devices, such as sharps with engineered sharps injury protections and needleless systems). CDC will also pursue mechanisms such as grants or CRADAs with industry to accelerate the development of products that have the potential for eliminating the opportunity for human error from process of administering injections.
- *Detection and Tracking* - \$9 million would be used for detection and tracking in order to enable states to investigate outbreaks of hepatitis and other potential pathogens related to injection safety. In addition, this funding would provide support to CDC for emergency response to assist states in responding to hepatitis outbreaks (i.e., Nevada), including genetic sequencing tests. Funding would support efforts including training at health departments related to safe injection practices and recognition of errors, and to enable rapid investigation and

intervention when errors are detected. The funding would also support the augmentation of survey capacity in outpatient settings to strengthen state capacity to detect infections that indicate systemic patient safety errors. The funding will enable CDC to provide support to states by providing training tools for surveyors, health department staff and epidemiologists to improve methods of monitoring adherence to correct practices and to provide tools for investigation, response and intervention strategies. Funds will also enable CDC to provide data analysis and feedback to states.

**HONORreform requests \$1 million for the Department of Health and Human Services (HHS)** to expand its current focus for reducing healthcare acquired infections (HAIs) from hospitals to all healthcare settings, including outpatient facilities. We are deeply concerned with the number of HAIs occurring in office-based settings, such as ambulatory care centers, infusion centers, and endoscopy clinics, due to a lack of adherence to basic infection control procedures. In the past year, over 100,000 patients across the country have been exposed to hepatitis and HIV from healthcare providers failing to adhere to proper safe injection practices and infection control.

**HONORreform requests \$10 million in general patient safety funds for the Agency for Healthcare Research and Quality's Ambulatory Patient Safety Program.** While much is known about risk and hazards in the hospital setting, the same cannot be said of ambulatory care setting. Few safety practices have been identified, and there is limited data on the nature of risk and hazards to patients and the threat to quality in the ambulatory care setting. As part of the overall AHRQ patient safety and quality improvement efforts, the identification, assessment, and modeling of risk and hazards prior to designing or implementing intervention strategy in ambulatory care is critical. In light of the growing number of incidents involving syringe reuse and hepatitis C transmission, this funding would enable AHRQ to expand its ambulatory safety and quality program "to identify the inherent risks in ambulatory settings and to develop potential solutions for protecting patients."

Mr. Chairman, on behalf of HONORreform, I would like to express my appreciation for this opportunity to present written testimony before the Subcommittee. The growing number of incidents involving syringe reuse and hepatitis C transmission in non-hospital settings across the country highlights the need for enhancing education, awareness and public health activities related to proper infection control and safe injection practices. I urge you to support our appropriations request as led by Representatives Berkley and Towns and signed onto by many of your colleagues, Representatives Titus, Fortenberry, Terry, and Carson for FY 2010.

TESTIMONY OF SARA AMUNDSON  
EXECUTIVE DIRECTOR, THE HUMANE SOCIETY LEGISLATIVE FUND  
FOR THE  
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION AND RELATED AGENCIES REGARDING THE  
NATIONAL INSTITUTES OF HEALTH AND NATIONAL INSTITUTE OF  
ENVIRONMENTAL HEALTH SCIENCES  
May 1, 2009

The Humane Society Legislative Fund (HSLF) supports a strong commitment by the federal government to research, development, standardization, validation and acceptance of non-animal and other alternative test methods. We are also submitting our testimony on behalf of The Humane Society of the United States and Doris Day Animal League, representing more than 11 million members and supporters. Thank you for the opportunity to present testimony relevant for the fiscal year 2010 budget request for the National Institute of Environmental Health Sciences (NIEHS) for the fiscal year 2010 activities of the National Toxicology Program Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM), the support center for the Interagency Coordinating Committee for the Validation of Alternative Test Methods (ICCVAM).

Function of the ICCVAM

The ICCVAM performs a valuable function for regulatory agencies, industry, public health and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the federal regulatory agencies that regulate the particular endpoint the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test methods as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulator burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test methods. In addition, from the perspective of animal protection advocates, ICCVAM can serve to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce or replace animals, should be expeditiously integrated into federal toxicological regulations, requirements and recommendations.

#### History of the ICCVAM

The ICCVAM is currently composed of representatives from the relevant federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for NIEHS to “(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use.” In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97-3981, “Validation and Regulatory Acceptance of Toxicological Test Methods.” This report, and subsequent revisions, has become the sound science guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS’ NICEATM. Representatives from federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM’s Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, several methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. In addition, the ICCVAM is working to streamline assessment of methods from the European Union (EU) that have already been validated for use within the EU. The open public comment process, input by interested stakeholders and the continued commitment by the federal agencies has led to ICCVAM’s success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

#### Request for Committee Report Language

In 2006, the NICEATM/ICCVAM at the request of the U.S. Congress began a process of developing a five-year roadmap for assertively setting goals to prioritize ending the use of antiquated animal tests for specific endpoints. The HSLF and other national animal protection organizations provided extensive comments on the process and priorities for the roadmap.

While the stream of methods forwarded to the ICCVAM for assessment has remained relatively steady, it is imperative that the ICCVAM take a more proactive role in isolating areas where new methods development is on the verge of replacing animal tests. These areas should form a collective call by the federal agencies that compose ICCVAM to fund any necessary additional research, development, validation and validation assessment that is required to eliminate the animal methods. We also strongly urge the NICEATM/ICCVAM to closely coordinate research, development and validation efforts with its European counterpart, the European Centre for the Validation of Alternative Methods (ECVAM) to ensure the best use of available funds and sound

science. This coordination should also reflect a willingness by the federal agencies comprising ICCVAM to more readily accept validated test methods proposed by the ECVAM to ensure industry has a uniform approach to worldwide chemical safety evaluation.

National Institutes of Health Support For - *Toxicity Testing in the 21<sup>st</sup> Century: A Vision and a Strategy*

In February, the National Institutes of Health (NIH) launched an ambitious collaboration with the Environmental Protection Agency (EPA) to dramatically transform the way drugs, consumer products, pesticides, and other chemicals are assessed for safety. The new approach will use isolated cells, molecular targets, and lower organisms such as roundworms, instead of laboratory animals. According to the NIH, the research collaboration is expected “to generate data more relevant to humans; expand the number of chemicals that are tested; and reduce the time, money and number of animals involved in testing.”

The new program, formalized by a memorandum of understanding (MOU), was unveiled at a February 14<sup>th</sup> press conference that featured Elias Zerhouni, director of the NIH, Francis Collins, head of the National Human Genome Research Institute (NHGRI), and other leading government scientists. The rationale behind the program was described in an article entitled “Transforming Environmental Health Protection” in the prestigious scientific journal *Science*.

The tripartite arrangement is designed to capitalize on the NIH Chemical Genomics Center's high-speed, automated screening robots to test compounds for toxicity; the experimental toxicology expertise of the National Toxicology Program, which is headquartered at the NIH's National Institute of Environmental Health Sciences; and the computational toxicology capabilities at the EPA's National Center for Computational Toxicology.

The government collaboration seeks to implement a June 2007 report by the National Research Council entitled *Toxicity Testing in the 21<sup>st</sup> Century: A Vision and a Strategy*, which calls for a sustained, well-funded effort across the toxicology community to shift the traditional toxicity-testing paradigm away from its heavy reliance on animal testing and towards high-throughput systems that monitor perturbations in toxicity pathways.

The government project could be seen as a successor, with equally visionary possibilities for biology, to Dr. Collins and NHGRI's highly successful Human Genome Project. In order for the new vision to be fully realized within a decade, what is needed is a well-funded government effort that would attract additional partners and resources from interested industries and overseas governments. According to the MOU, the collective budget for the project is yet to be determined.

## Links:

NIH/NIEHS press release:

<http://www.niehs.nih.gov/news/releases/2008/toxrelease.cfm>

Memorandum of understanding:

<http://www.niehs.nih.gov/news/releases/2008/docs/ntpncgcepamou.pdf>

Science article:

<http://www.niehs.nih.gov/news/releases/2008/docs/906.pdf>

National Research Council report:

[http://books.nap.edu/openbook.php?record\\_id=11970](http://books.nap.edu/openbook.php?record_id=11970)

We respectfully request the Subcommittee consider the following report language for the fiscal year 2010 House Labor, Health and Human Services, Education and Related Agencies Appropriations bill:

“The Committee acknowledges the publication of the NICEATM/ICCVAM Five-Year Plan but remains concerned by the slow pace at which federal agencies have moved to adopt regulations that would replace, reduce or refine the use of animals in testing. The Committee therefore requests that NICEATM/ICCVAM hold an initial workshop, based upon input received from a workshop steering committee with representation of scientists from academia, federal government, animal welfare organizations and industry, on “Challenges to Incorporating Alternative Methods into US Federal Agency Programs.” The Committee also requests that NICEATM/ICCVAM convene a workshop in fiscal year 2010 to assess the difficulty of obtaining high quality relevant data for validating alternative methods, which is a significant barrier to validation and acceptance. NICEATM/ICCVAM are also urged to establish timetables for completion of all validation reviews that are currently under way.”

House Committee on Appropriations  
 Subcommittee on Labor HHS  
 The Humane Society of the United States  
 on the FY 2010 Budget  
 May 1, 2009

**HOUSE COMMITTEE ON APPROPRIATIONS  
 SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
 EDUCATION AND RELATED AGENCIES**

**TESTIMONY BY NANCY PERRY, VICE PRESIDENT OF GOVERNMENT AFFAIRS FOR  
 THE HUMANE SOCIETY OF THE UNITED STATES,  
 ON THE FY 2010 BUDGET  
 May 1, 2009**

On behalf of The Humane Society of the United States (HSUS) and our 11 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priority for the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in Fiscal Year 2010. We are also submitting our testimony on behalf of The Humane Society Legislative Fund (HSLF) and the Doris Day Animal League. Thank you for the opportunity to present testimony relevant for the Fiscal Year 2010 budget request.

The HSUS requests that no federal funding be appropriated for (1) invasive research on chimpanzees, (2) breeding of chimpanzees for research, or for (3) the transfer of government-owned chimpanzees to private hands (including endowments for their maintenance) unless for retirement to appropriate sanctuary. The basis of our request can be found below.

**Breeding of Chimpanzees for Research**

- The National Center for Research Resources (NCRR) of the National Institutes of Health (NIH), responsible for the oversight and maintenance of federally-owned chimpanzees, has announced a permanent end to funding the breeding of federally owned and supported chimpanzees primarily due to the excessive costs of lifetime care of chimpanzees in laboratory settings. We recently discovered that the government has provided millions of dollars in recent years for chimpanzee breeding. Therefore, we seek to ensure that neither the NIH nor any other federal agency provides funding for breeding of government-owned chimpanzees due to the future financial implications to the government and taxpayers of continuing to do so, particularly during this difficult economic time.
- The cost of maintaining chimpanzees in laboratories is exorbitant, totaling up to \$8.5 million each year for the current population of approximately 500 federally owned or supported chimpanzees (approximately \$54 per day per chimpanzee; over \$1,000,000 per chimpanzee's 60-year lifetime). Breeding of additional chimpanzees into laboratories will only perpetuate a number of burdens on the government.
- The U.S. currently has a surplus of chimpanzees available for use in research due to overzealous breeding for HIV research and subsequent findings that they are a poor HIV model.<sup>1</sup>



House Committee on Appropriations  
 Subcommittee on Labor HHS  
 The Humane Society of the United States  
 on the FY 2010 Budget  
 May 1, 2009

- Expansion of the chimpanzee population in laboratories only creates more concerns than presently exist about their quality of care.
- Use of chimpanzees in research raises strong public concerns.

#### **Transfer of ownership of government-owned chimpanzees**

- If the government-owned and supported chimpanzees leave the federal system and are transferred into private hands with an accompanying federally-funded endowment, their lifetime support will not be guaranteed as required now by the CHIMP Act and their transfer to a suitable sanctuary will be highly unlikely. These chimpanzees will instead be warehoused and/or used for research for their entire lifetime—with the backing of the government through an endowment. This will surely lead to a public outcry.
- If private industry breeds and uses chimpanzees in invasive research with federal endowment money, the private sector would be unfairly, and perhaps illegally, benefiting from federally owned “resources” meant for the betterment of the American public, not for the profit of private industry.
- To date, the private sector has been less than fiscally responsible for the life time care of chimpanzees who they have used for private profit. Even in the situations where they eventually retire their chimpanzees, private users rarely offer financial compensation for their chimpanzees’ lifetime care and on the few occasions that they have offered some financial compensation, it falls far short of what is actually needed.

We instead urge the government to transfer all 500 government-owned chimpanzees to the national sanctuary system and appropriate a portion of the funding currently being given to chimpanzee laboratories to the sanctuary system. A transfer of the chimpanzees to sanctuary would: (1) consolidate and lessen chimpanzee maintenance costs, (2) provide the chimpanzees with better care, and (3) offer the public the humane solution they are asking for.

#### **Background and history**

Beginning in 1995, the National Research Council (NRC) confirmed a chimpanzee surplus and recommended a moratorium on breeding of federally owned or supported chimpanzees<sup>1</sup>, who now number approximately 500 of the more than 1000 total chimpanzees available for research in the U.S. On May 22, 2007 the NCRR of NIH announced a permanent end to the funding of chimpanzee breeding, which applies to all federally-owned and supported chimpanzees as well as NIH-funded research. Further, it has also been noted that “a huge number” of chimpanzees are not being used in active research protocols and are therefore “just sitting there.”<sup>2</sup> If no breeding is allowed, it is projected that the government will have almost no financial responsibility for the

chimpanzees it owns within 30 years due to the age of the population—any breeding today will extend this financial burden to 90 years.

There is no justification for breeding of additional chimpanzees for research; therefore lack of federal funding for breeding will ensure that no breeding of federally owned or supported chimpanzees for research will occur in FY 2010.

#### **Concerns regarding chimpanzee care in laboratories**

A nine month undercover investigation by The HSUS at University of Louisiana at Lafayette New Iberia Research Center (NIRC)—the largest chimpanzee laboratory in the world—revealed some chimpanzees living in barren, isolated, conditions and documented over 100 alleged violations of the Animal Welfare Act at the facility in regards to chimpanzees. The U.S. Department of Agriculture (USDA) and NIH's Office of Laboratory Animal Welfare (OLAW) have since launched formal investigations into the facility and NIRC was cited for several violations of the Animal Welfare Act during an initial site visit.

Aside from the HSUS investigation, inspections conducted by the USDA demonstrate that basic chimpanzee housing requirements are often not being met. Inspection reports for two other federally funded chimpanzee facilities reported housing of chimpanzees in less than minimal space requirements, inadequate environmental enhancement, and/or general disrepair of facilities. These problems add further argument against the breeding of even more chimpanzees.

#### **Chimpanzees have often been a poor model for human health research**

The scientific community recognizes that chimpanzees are poor models for HIV because chimpanzees do not develop AIDS. Similarly, chimpanzees do not model the course of the human hepatitis C virus yet they continue to be used for this research, adding to the millions of dollars already spent without a sign of a promising vaccine. According to the chimpanzee genome, some of the greatest differences between chimpanzees and humans relate to the immune system<sup>3</sup>, calling into question the validity of infectious disease research using chimpanzees.

#### **Ethical and public concerns about chimpanzee research**

Chimpanzee research raises serious ethical issues, particularly because of their extremely close similarities to humans in terms of intelligence and emotions. Americans are clearly concerned about these issues: 90% believe it is unacceptable to confine chimpanzees individually in government-approved cages (as we documented during our investigation at NIRC); 71% believe that chimpanzees who have been in the laboratory for over 10 years should be sent to sanctuary for retirement<sup>4</sup>; and 54% believe that it is unacceptable for chimpanzees to “undergo research which causes them to suffer for human benefit.”<sup>5</sup>

House Committee on Appropriations  
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**We respectfully request the following bill or committee report language:**

**“The Committee directs that no funds provided in this Act be used to support invasive research on chimpanzees, the breeding of chimpanzees for research, research that requires breeding of chimpanzees, or to support the transfer of ownership of federally owned chimpanzees to private entities, including endowments for their maintenance, with the exception of a transfer to an appropriate sanctuary that meets the national chimpanzee sanctuary system standards.”**

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2010. We hope the Committee will be able to accommodate this modest request that will save the government a substantial sum of money, benefit chimpanzees, and allay some concerns of the public at large. Thank you for your consideration.

#### References

1. NRC (National Research Council) (1997) *Chimpanzees in research: strategies for their ethical care, management and use*. National Academies Press: Washington, D.C.
2. Cohen, J. (2007) Biomedical Research: The Endangered Lab Chimp. *Science*. 315:450-452.
3. The Chimpanzee Sequencing and Analysis Consortium/Mikkelsen, TS, *et al.*, (1 September 2005) Initial sequence of the chimpanzee genome and comparison with the human genome, *Nature* 437, 69-87.
4. 2006 poll conducted by the Humane Research Council for Project Release & Restitution for Chimpanzees in laboratories
5. 2001 poll conducted by Zogby International for the Chimpanzee Collaboratory

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**Infectious Diseases Society of America's (IDSA) Statement Concerning  
Fiscal Year 2010 Funding at the Department of Health and Human Services, the Centers for  
Disease Control and Prevention, and National Institutes of Health**

**Submitted to the House Appropriations Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies**

**May 1, 2009**

The Infectious Diseases Society of America (IDSA) appreciates this opportunity to speak in support of federal efforts to prevent, detect and respond to infectious diseases in the United States and abroad as part of the Fiscal Year (FY) 2010 funding cycle. IDSA represents more than 8,500 infectious diseases physicians and scientists devoted to patient care, prevention, public health, education and research. Our members care for patients of all ages with serious infections, including meningitis, pneumonia, tuberculosis (TB), antibiotic-resistant bacterial infections such as methicillin-resistant *Staphylococcus aureus* (MRSA), and those with cancer or transplants who have life-threatening infections caused by unusual microorganisms, food poisoning, and HIV/AIDS, as well as emerging infections like the 2009 H1N1 virus (swine influenza) and severe acute respiratory syndrome (SARS).

**2009 H1N1 Virus (Swine Influenza)**

IDSA's leadership strongly commends the Administration's efforts to date in managing and responding to the 2009 H1N1 outbreak. Of critical importance, experts and scientists are driving key decisions. The leadership of the Centers for Disease Control and Prevention (CDC) and the Department of Health and Human Services (HHS) has been strong, and their coordination with other federal, state, and local governments is clear. Undeniably, the investments and subsequent preparations the country has made since the *National Strategy for Pandemic Influenza* was issued in November 2005 are paying off. As the 2009 H1N1 virus outbreak unfolds, we are witnessing firsthand the important role a robust public health infrastructure plays in rapidly detecting and containing disease outbreaks. Yet, additional resources are needed to adequately respond to the 2009 H1N1 outbreak as well as to continue to prepare our nation for other bioemergencies.

IDSA supports at least an additional \$1.5 billion to complete the funding to implement the *National Strategy for Pandemic Influenza*. This money will support the development of a 2009 H1N1 virus vaccine and the replenishment and building of the Strategic National Stockpile. Responding to the 2009 H1N1 outbreak will require using a significant portion of the currently stockpiled antiviral medications (oseltamivir and zanamivir) and other medical equipment such as respirator masks. Some of this funding also should support state and local health departments so they may adequately prepare for and respond to the 2009 H1N1 virus and other infectious diseases outbreaks. State and local officials are the front line responders to outbreaks, yet they have not received federal funding for pandemic flu preparedness since FY 2006. IDSA believes that at least \$350 million is needed annually to adequately maintain state and local pandemic preparedness activities. IDSA also strongly supports strengthening funding for ongoing pandemic influenza preparedness activities at CDC, the Food and Drug Administration (FDA), National Institutes of Health (NIH), and HHS' Office of the Secretary.

Congress also must fully fund the Biomedical Advanced Research and Development Authority (BARDA) within HHS so that the United States can begin to realize goals envisioned under the Pandemic and All-Hazards Act enacted in 2006 to address a broad spectrum of biological threats in addition to pandemic influenza. IDSA recommends that \$1.7 billion of multi-year appropriations be allocated to BARDA in FY 2010 to fund biological therapeutics, diagnostics, vaccines and other technologies. Such funding would help ensure the availability of resources throughout the advanced stages of development and the flexibility for BARDA to partner effectively with industry.

#### Centers for Disease Control and Prevention (CDC)

A strong CDC is essential to the United States' efforts to rapidly detect and control infectious diseases as witnessed by the current H1N1 outbreak. CDC is the primary federal agency responsible for conducting and supporting public health protection through health promotion, prevention, preparedness, and research. IDSA recommends increasing funding for CDC's core programs to \$8.6 billion, to enable it to maintain a strong public health infrastructure and protect Americans from public health threats and emergencies.

IDSA is especially concerned about CDC's Infectious Diseases program budget, which supports critical management and coordination functions for infectious diseases science, program, and policy, including related specific epidemiology and laboratory activities. IDSA recommends an FY2010 funding level of \$2.7 billion for CDC's Infectious Diseases programs.

Within the Infectious Disease programs' proposed budget, the agency's already severely strapped Antimicrobial Resistance budget stands at \$16.9 million. This vital program is necessary to help combat the rising tide of drug resistance, a critical medical problem marked most publicly by the upsurge in methicillin-resistant *Staphylococcus aureus* (MRSA) and other drug-resistant bacterial infections. Antimicrobial resistance also has serious implications for our collective response to the 2009 H1N1 virus. Viruses are unpredictable, and should the 2009 H1N1 virus develop resistance to oseltamivir and zanamivir, our ability to respond effectively to the influenza outbreak will significantly diminish. For these reasons, IDSA recommends increasing FY2010 funding for resistance programs at CDC by \$48 million, to a total of \$65 million. Such funding increases will enable CDC to more effectively gather morbidity and mortality data related to resistance, track the development of dangerous resistant bugs as they develop, educate physicians, patients and the public about the need to protect the long-term effectiveness of antimicrobial drugs, and strengthen infection control activities across the United States. This recommended level coincides well with an internal CDC professional judgment prepared last year which, unfortunately, was not provided to Congress.

The Emerging Infectious Diseases (EI) budget line boosts the agency's capacity to nimbly identify and respond to emerging infections, such as the 2009 H1N1 virus. Much of CDC's infectious diseases funding is highly disease-targeted, making it difficult to fund cross-cutting or emergent needs. Unique in its flexibility, the EI line supports dozens of research and surveillance programs that address new and unpredictable threats. Such threats have included rabies, rotavirus, food-borne diseases, Ebola and SARS. Inadequate funding would severely affect CDC's laboratory capacity, research grants to academic partners, and support for state public health departments and public health laboratories and would reduce CDC's flexibility in setting priorities and taking action

against new infections that may emerge throughout the year. IDSA recommends, at a minimum, that the Other Emerging Infectious Diseases line item be increased to \$160 million for FY2010.

Immunizing our population against vaccine-preventable diseases is one of our country's greatest public health achievements. Through CDC's Section 317 Program, which funds state and local immunizations efforts, the United States has made significant progress toward eliminating vaccine-preventable diseases among children. IDSA applauds the actions by the Congress over the past year to increase funding for this program in the American Recovery and Reinvestment Act and in the Fiscal Year 2009 Omnibus Appropriations bill. At a time when new CDC-recommended vaccines are available and a greater commitment to immunizations for both children and adults is necessary, we need to continue to increase access to this critical intervention that saves lives and millions of dollars in unnecessary medical spending. To build on this important effort, IDSA recommends a funding level for the Section 317 Program of \$802 million in FY2010.

IDSA also supports changes which will significantly strengthen the Section 317 Program's support for adult and adolescent immunization. Each year, more than 46,000 adults die of vaccine-preventable diseases. Costs related to illnesses from adult vaccine-preventable diseases are approximately \$10 billion. IDSA recommends the establishment of distinct funding floors for adult vaccine purchase and infrastructure in amounts sufficient to cover immunization of the majority of under-insured and uninsured adults with all CDC-recommended vaccines.

Last year, Congress passed landmark legislation in the Comprehensive Tuberculosis Elimination Act of 2008. This bill authorizes a number of actions that will shore up state TB control programs, enhance U.S. capacity to deal with the serious threat of drug-resistant tuberculosis, and escalate our efforts to develop urgently needed "tools," such as drugs, diagnostics and vaccines. Realizing these goals will require additional resources. At a minimum, it is critical that the funding authorized for FY2010 in this important law – \$210 million – be appropriated for the CDC Division of TB Elimination. The bill also separately authorized \$100 million for development of TB diagnostics, treatments and prevention tools, which IDSA also supports for inclusion in FY2010 appropriations.

HIV prevention and surveillance activities at CDC are critical to reducing the number of new cases occurring annually in the United States. Sufficient resources must be devoted to HIV prevention to support CDC's portfolio of prevention programs, including the initiative to identify people with HIV/AIDS earlier through routine HIV screening. This program will lead to lifesaving care sooner and will help to prevent further transmissions. IDSA supports funding in the amount of \$1.57 billion for these programs in FY2010. We also support funding of \$2.81 billion for the Ryan White CARE Act programs within the Health Resources and Services Administration and urge you to increase funding for critical Part C medical care by \$68.4 million, to a total of \$270.3 million for Part C programs. Ryan White programs provide a vital link in our health care safety net and are currently struggling to meet the need for HIV services in communities across the country.

#### National Institutes of Health (NIH)

The National Institutes of Health (NIH) is the single-largest funding source for infectious diseases research in the United States and the life-source for many academic research centers. The NIH-funded work conducted at these centers lays the groundwork for advancements in treatments, cures, and other medical technologies. Between 2003 and 2009, NIH lost 13 percent of its

purchasing power due to the rate of biomedical research inflation and stagnating annual budgets. Because of the flat budget, three out of four research proposals submitted to NIH were not funded. Peer reviewers were forced to become more risk averse, leading to a narrowing of scientific vision and a diminishing rate of medical advancement. Without medical advancements, thousands of Americans will have to wait longer for the cures they need.

IDSA is extremely pleased that the recently enacted American Recovery and Reinvestment Act provided \$10 billion in additional funding to support NIH's research efforts in 2009 and 2010. Congress rightfully acknowledged the role of scientific research in stimulating the economy. It is vital, however, that this long overdue increase in funding be sustained and become part of NIH's baseline. Making this increase permanent ultimately will translate into long-term improvements in human health, both domestically and globally.

NIH's Fogarty International Center is at the forefront of global health and is a leader in extending the U.S. federal biomedical enterprise abroad. It taps innovative thinking from all parts of the world and fosters important scientific partnerships. Through Fogarty, the United States has supported research and research training programs conducted by both U.S. and foreign investigators across a wide range of infectious diseases and needs, including HIV/AIDS, malaria, and tuberculosis. The Center's efforts have led to improved local health outcomes -- but so much more can be done. For this reason, IDSA strongly supports increasing Fogarty's funding level in FY2010 to \$100 million -- an increase of \$31.3 million. These additional resources will enable Fogarty to increase research training initiatives, forge new partnerships between U.S. and foreign research institutions, and conduct much-needed implementation research to increase the effectiveness of international programs.

IDSA also proposes an increase in antimicrobial resistance research funding at NIH's National Institute of Allergies and Infectious Diseases (NIAID) of \$100 million in FY2010, bringing overall funding in this area to \$328 million. This will allow NIAID to strengthen clinical research and establish a clinical trials network to study resistant infections as well as antibacterial use and development. Well-designed, multi-center, randomized, controlled trials would create an excellent basis of evidence from which coherent and defensible recommendations could be developed.

#### Food and Drug Administration

Additionally, in the Agriculture Appropriations bill, IDSA supports a strengthening of antimicrobial resistance efforts at FDA. Specifically we support a \$20 million increase in antimicrobial resistance funding for FDA in FY2010, bringing the agency's resistance funding to \$44 million. This will allow FDA to establish and periodically update antibiotic susceptibility breakpoints based on testing and data collection, including through the purchase of vendor data; fund Critical Path initiatives for antibiotics; more aggressively review the safety of antibiotic use in food animals; and quicken its pace in developing critical guidance for industry on antibiotic clinical trial designs.

Today's investment in infectious diseases research, prevention, and treatments will pay significant dividends in the future by dramatically reducing health care costs and improving the quality of life of millions of Americans and others. It also will continue to enable federal agencies to respond effectively and efficiently to the 2009 H1N1 virus and other potentially devastating outbreaks.

**STATEMENT OF  
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**ON BEHALF OF THE  
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**REGARDING FISCAL YEAR 2010 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL  
INSTITUTES OF DIABETES AND DIGESTIVE AND KIDNEY  
DISEASES**

**SUBMITTED TO THE  
HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES**

**MAY 1, 2009**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2010:**

- **PROVIDE A FUNDING INCREASE OF AT LEAST 7% FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND ITS INSTITUTES AND CENTERS.**
- **URGE THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) TO PRIORITIZE AND IMPLEMENT THE RECENTLY RELEASED RESEARCH RECOMMENDATIONS OF THE NATIONAL COMMISSION ON DIGESTIVE DISEASES.**
- **URGE NIH AND NIDDK TO EXPAND THE RESEARCH PORTFOLIO ON FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS, SUCH AS IRRITABLE BOWEL SYNDROME.**



Thank you for the opportunity to present this written statement regarding the importance of functional gastrointestinal and motility disorders research.

Since our establishment in 1991, the International Foundation for Functional Gastrointestinal Disorders (IFFGD) has been dedicated to increasing awareness of functional gastrointestinal and motility disorders among the public, health professionals, and researchers. We also work to bolster digestive disease research and generate new treatment options for patients. For example, IFFGD worked with the NIDDK, the National Institute of Child Health and Human Development (NICHD), and the Office of Medical Applications of Research (OMAR) to facilitate an *NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults*, which was held in December of 2007. Furthermore, I served on the National Commission on Digestive Diseases (NCDD) which recently released a long-range road map for digestive disease research, entitled *Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases*.

The majority of diseases and disorders we address have no cure and treatment options are often limited. We have yet to completely understand the mechanisms of the underlying conditions. Patients face a life of learning to manage a chronic illness that is accompanied by pain and an unrelenting myriad of gastrointestinal symptoms. The medical and indirect costs associated with these diseases are enormous; estimates range from \$25 - \$30 billion annually. Economic costs spill over into the workplace, and are reflected in work absenteeism and lost productivity. Furthermore, the human toll is not only on the individual but also on the family. In essence, these diseases account for lost opportunities for the individual and society.

#### **IRRITABLE BOWEL SYNDROME (IBS)**

IBS strikes people from all walks of life. It affects 30 to 45 million Americans and results in significant human suffering and disability. This chronic disease is characterized by a group of symptoms, which include abdominal pain or discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. Although the cause of IBS is unknown, we do know that this disease needs a multidisciplinary approach in research and treatment.

IBS can be emotionally and physically debilitating. Due to persistent pain and bowel unpredictability, individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home.

Numerous research recommendations regarding IBS were included as components of the NCDD's Long-Range Research Plan for Digestive Diseases. For FY 2010, IFFGD urges Congress to review the NCDD's Report, and provide NIH and NIDDK with the resources necessary to adequately implement the plan's recommendations.

#### **FECAL INCONTINENCE**

At least 12 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and in the elderly of both sexes. Often it is a symptom associated with various neurological diseases and many cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, uterine cancer, and a host of other diseases.

Damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction can cause fecal incontinence. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most attempt to hide the problem for as long as possible. They withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly burdens families and is the primary reason for nursing home admissions, an already huge social and economic burden in our increasingly aged population.

In November of 2002, IFFGD sponsored a consensus conference entitled, *Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities*. Among other outcomes, the conference resulted in six key research recommendations including more comprehensive identification of quality of life issues; improved diagnostic tests for affecting management strategies and treatment outcomes; development of new drug treatment compounds; development of strategies for primary prevention of fecal incontinence associated with childbirth; and attention to the process of stigmatization as it applies to the experience of individuals with fecal incontinence.

In December of 2007, IFFGD collaborated with NIDDK, NICHD, and OMAR on the *NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults*. The goal of this conference was to assess the state of the science and outline future priorities for research on both fecal and urinary incontinence; including, the prevalence and incidence of fecal and urinary incontinence, risk factors and potential prevention, pathophysiology, economic and quality of life impact, current tools available to measure symptom severity and burden, and the effectiveness of both short and long term treatment. For FY 2010, IFFGD urges Congress to review the Conference's Report and provide NIH with the resources necessary to effectively implement the report's recommendations.

#### **GASTROESOPHAGEAL REFLUX DISEASE (GERD)**

Gastroesophageal reflux disease, or GERD, is a common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. Sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. One uncommon but serious complication is Barrett's esophagus, a potentially pre-cancerous condition associated with esophageal cancer. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. There are several treatment options available for individuals suffering from GERD. Nonetheless, treatment response varies from person to person, is not always effective, and long-term medication use and surgery expose individuals to risks of side-effects or complications.

Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year. GER results from an immature upper gastrointestinal motor development. The prevalence of GER is increased in premature infants. Many infants require medical therapy in order for their symptoms to be controlled. Up to 25% of older children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction. In this population, the

natural history of GER is similar to that of adult patients, in whom GER tends to be persistent and may require long-term treatment.

#### **GASTROPARESIS**

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, including being present in 30% to 50% of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications, especially narcotic pain medications. In many patients the cause of the gastroparesis cannot be found and the disorder is termed idiopathic gastroparesis. Over the last several years, as more is being found out about gastroparesis, it has become clear this condition affects many people and the condition can cause a wide range of symptom severity.

#### **CYCLIC VOMITING SYNDROME**

Cyclic vomiting syndrome (CVS) is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea, vomiting, and other symptoms (abdominal pain, prostration, and lethargy) lasts hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in a variety of age groups including adults. Patients with these symptoms often go for years without correct diagnosis. The condition leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Better understanding, through research, of mechanisms that underlie upper gastrointestinal function and motility involved in sensations of nausea, vomiting and abdominal pain is needed to help identify at risk individuals and develop more effective treatment strategies.

#### **SUPPORT FOR CRITICAL RESEARCH**

IFFGD urges Congress to provide the necessary funding for the expansion of the research activities at NIDDK and the Office of Research on Women's Health (ORWH) regarding functional gastrointestinal disorders and motility disorders. Additional funding will allow necessary growth of the research portfolios on functional gastrointestinal disorders and motility disorders at NIDDK and ORWH, and also facilitate implementation of the NCDD's research recommendations.

Recent years of near level-funding at NIH have negatively impacted the mission of its Institutes and Centers. For this reason, IFFGD applauds initiatives like Senator Arlen Specter's (R-PA) successful effort to provide NIH with \$10.4 billion in stimulus funds. IFFGD urges this Subcommittee to show strong leadership in pursuing substantial funding increase through the regular appropriations process in FY 2010.

*For FY 2010, IFFGD recommends a funding increase of at least 7% for NIH and its Institutes and Centers.*

Thank you for the opportunity to present the views of the functional GI disorders community.

**Submitted by:**  
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**Testimony of the International Myeloma Foundation  
Regarding Fiscal Year 2010 Appropriations for  
Myeloma Cancer Programs**

**Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives**

**April 30, 2009**

The International Myeloma Foundation (IMF) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2010 funding for myeloma cancer programs. The IMF is the oldest and largest myeloma foundation dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

To ensure that myeloma patients have access to the comprehensive, quality care they need and deserve, the IMF advocates on-going and significant federal funding for myeloma research and its application. The IMF stands ready to work with policymakers to advance policies and programs that work toward prevention and a cure for myeloma and for all other forms of cancer.

**Myeloma Background**

Myeloma is a cancer in the bone marrow affecting production of red cells, white cells and stem cells. It is also called "multiple myeloma," because multiple areas of bone marrow may be involved. Myeloma is the second most common blood cancer after lymphomas, affecting an estimated 750,000 people worldwide and its prevalence appears to be increasing significantly.

No one knows the exact causes of myeloma. Doctors can seldom explain why one person develops this disease and another does not. Research has shown that people with certain risk factors such as age and race are more likely than others to develop myeloma. Growing older increases the chance of developing multiple myeloma as most people with myeloma are diagnosed after age 65. However, in recent years the diagnosis of myeloma in people 40 years of age and younger appears to have become more common as our ability to detect and diagnose this disease has improved. The risk of myeloma is highest among African Americans and lowest among Asian Americans.

Scientists are studying other possible risk factors for myeloma. Toxic chemicals (for example, agricultural chemicals and Agent Orange used in Vietnam), radiation (including atomic radiation), and several viruses (including HIV, hepatitis, herpes virus 8, and others) are associated with an increased risk of myeloma and related diseases.

According to the American Cancer Society, 19,920 Americans were expected to be diagnosed with myeloma and 10,690 would lose their battle with this disease in 2008. Even while they live with the disease, myeloma patients can suffer debilitating fractures and other bone disorders, severe side effects of their treatment, and other problems that profoundly affect their quality of life, and significantly impact the cost of their health care. Despite these grim statistics, significant gains in the battle against myeloma have been made through our nation's investment in cancer research and its application. Research holds the key to improved myeloma prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless unless we can deliver them to all Americans in need.

#### **Sustain and Seize Cancer Research Opportunities**

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). The IMF advocates \$33.3 billion for NIH in FY 2010. This will allow NIH to sustain and build on its research progress resulting from the recent doubling of its budget while avoiding the severe disruption to that progress that would result from a minimal increase. Myeloma research is producing extraordinary breakthroughs – leading to new therapies that translate into longer survival and improved quality of life for myeloma patients. Although myeloma was once considered a death sentence with limited options for treatment, myeloma is an example of the progress that can be made and the work that still lies ahead in the war on cancer. Many myeloma patients are living proof of what innovative drug development and clinical research can achieve - sequential remissions, long-term survival and good quality of life. But these achievements are not a substitute for a cure and therefore the IMF calls upon Congress to allocate \$6 billion to the National Cancer Institute (NCI) in FY 2010 to continue our battle against myeloma and its sequelae.

#### **Boost Our Nation's Investment in Myeloma Prevention, Early Detection, and Awareness**

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering at the community level what is learned from research. Therefore, the IMF joins with our partners in the cancer community – including One Voice Against Cancer (OVAC) – in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven efforts in such areas as cancer prevention, early detection, and risk reduction. Specifically, the IMF advocates the appropriation of \$471 million in FY 2010 for CDC's cancer prevention and control initiatives.

Within that allocation, the IMF specifically advocates \$6 million for the Geraldine Ferraro Blood Cancer Program. Authorized under the Hematological Cancer Research Investment and

Education Act of 2002, this program was created to provide public and patient education about blood cancers, including myeloma.

With grants from the Geraldine Ferraro Blood Cancer Program, the IMF has successfully promoted awareness of myeloma, particularly in the African-American community and other underserved communities. IMF accomplishments include the production and distribution of more than 4,500 copies of an informative video which addresses the importance of myeloma awareness and education in the African-American community to churches, community centers, inner-city hospitals, and Urban League offices around the country, increased African-American attendance at IMF Patient and Family Seminars (these seminars provide invaluable treatment information to newly diagnosed myeloma patients), increased calls by African-American myeloma patients, family members, and caregivers to the IMF myeloma hotline, and the establishment of additional support groups in inner city locations in the United States to assist underserved areas with myeloma education and awareness campaigns. Furthermore, the more than 90 IMF-affiliated patient support groups in the U.S. also made this effort their main goal during "Myeloma Awareness Week" in October 2005.

An allocation of \$6 million in FY 2010 will allow this important program to continue to provide patients – including those populations at highest risk of developing myeloma – with educational, disease management and survivorship resources to enhance treatment and prognosis.

#### **Conclusion**

The IMF stands ready to work with policymakers to advance policies and support programs that work toward prevention and a cure for myeloma. Thank you for this opportunity to discuss the FY 2010 funding levels necessary to ensure that our nation continues to make gains in the fight against myeloma.

**Vicki and Fred Modell, CoFounders  
Jeffrey Modell Foundation  
(212) 819-0200  
fmodell@jmfworld.org**

Mr. Chairman:

Thank you for the opportunity to present to you our testimony concerning the activities of the Jeffrey Modell Foundation (JMF) dedicated to Primary Immunodeficiency (PI). As you know, most of our programs are conducted in partnership with various governmental agencies under the jurisdiction of this subcommittee. We very much appreciate the support, generosity and kindness of spirit that we have received from the Members and staff of this subcommittee and look forward to continuing to work together closely in the future.

As a baseline, Mr. Chairman, please let me make clear the following four fundamental points:

- JMF programs **always include our own investment of funds** and resources, thereby assuring accountability.
- JMF programs **improve patients' quality of life issues** through prevention and earliest possible diagnosis.
- JMF programs, therefore, **lower healthcare costs.**
- JMF programs **save lives** as demonstrated in the 2008 Wisconsin newborn screening program.

All of the data concerning the impact of the education and awareness program that this subcommittee has long supported has been published in a leading scientific journal, *"Immunologic Research", Humana Press, January 13, 2009* and is entitled, **"From Genotype to Phenotype. Further Studies Measuring the Impact of a Physician Education and Public Awareness Campaign on Early Diagnosis and Management of Primary Immunodeficiencies"**.

#### **Physician Education and Public Awareness Campaign on Primary Immunodeficiencies**

Five years ago, Mr. Chairman, this subcommittee set us on a path to work with the Centers for Disease Control and Prevention (CDC) to create a physician education and public awareness program. Today, that program has far exceeded even our most optimistic dreams.

JMF has now generated more than \$100 million in donated media from television, radio, print, website, airport and mall dioramas. This translates to more than \$18 million annually and represents \$7 donated to support this campaign for every \$1 of government support appropriated by this subcommittee. But all that visibility would be meaningless if there were not real impact on the health of these patients. And, there are.

The number of **patients referred, tested, diagnosed and treated has more than doubled every year for the past 5 years** in which the campaign has been conducted.

The Jeffrey Modell Centers Network of Research, Diagnostic and Referral Centers now include 304 physicians, from 138 academic teaching hospitals and medical schools. Twenty-three of the 30 “Best Pediatric Hospitals” in the U.S. are designated Jeffrey Modell Centers. The physician-experts at these centers have provided JMF with data on more than 30,000 patients. And we can now pinpoint the specific disease, where the patient is treated, who is treating the patient, and how the patient is treated. This data can make an enormous contribution to registries not only in the U.S. but on a global platform.

After diagnosis and treatment, **physicians reported annual decreases of more than 70% in the number of severe infections, physician, hospital, and emergency room visits**, pneumonias, school/work days missed, days in hospital, acute infections, and days with chronic infections.

The consequences of these changes in patient outcomes were assigned economic values. JMF’s published study drew from the hospital accounting reports at the Centers for Medicare and Medicaid services. The specific hospital charges and length of stay data was obtained from the Hospital Cost and Utilization Project (HCUP), Nationwide In-patient Sample, under the auspices of the Agency for Healthcare Research and Quality (AHRQ).

The study showed that each undiagnosed patient costs the healthcare system \$102,736 annually in emergency room visits, hospitalizations, and medical treatment for severe complications. It costs \$22,696 annually to treat patients after they have been diagnosed—a **savings of more than \$80,000 per patient per year**.

The NIH states that “while individual primary immunodeficiency diseases are somewhat rare, affecting 500,000 Americans, this group of diseases may affect 1-2% of the U.S. population or 3 million–6 million Americans.” Using the most conservative estimate, **the minimum cost to the U.S. healthcare system for undiagnosed PI patients is over \$40 billion annually**. Ensuring that these patients are properly diagnosed makes enormous economic sense, not to mention their improved quality of life.

#### **Research Collaboration with NIH**

JMF established a \$12 million research partnership with 4 of the U.S. National Institutes of Health (NIH). The RO1 research grants solicit investigations on Primary Immunodeficiency (PI) diseases. JMF also established the Robert A. Good/Jeffrey Modell International Fellowship Program, funding the brightest young investigators from around the world, focused on PI and stem cell transplantation. JMF awarded 4 Fellowships in 2008 under this program.

Finally, in 2008, JMF established Endowed Chairs in Pediatric Immunology Research at Children’s Hospital Boston, Children’s Hospital Seattle, as well as the Jeffrey Modell Endowed Fellowship in Immunology Research at the University of Washington.



### **Newborn Screening for Primary Immunodeficiencies**

JMF and the State of Wisconsin launched the first newborn screening program for Severe Combined Immune Deficiency (SCID). Since January 2008, every baby born in the State of Wisconsin has been screened. The T Cell Receptor Excision Circles (TRECs) assay was utilized and the screening test identified a patient with a combined immunodeficiency disease. The baby received a life saving bone marrow transplant. The screening protocol has picked up several other newborns with life threatening disorders including Complete Di George Syndrome, T-Cell lymphopenia, and a disorder where white blood cells are unable to migrate to sites of infection. We anticipate that Massachusetts, Illinois, Connecticut, Texas, and New York will move forward with pilot programs in 2009.

At this date, the cost to screen for these life threatening diseases is \$5 per child. It is anticipated that this cost will decrease. There are approximately 4 million newborns per year in the United States. Thus, the outside cost to screen every newborn in the U.S. is estimated to be less than \$20 million.

### **SPIRIT – Software for Primary Immunodeficiency Recognition Intervention and Tracking**

JMF brought its 2008 data to the annual meeting of the Managed Care Network (MCN). Senior executives and medical directors of private and Medicare/Medicaid health plans nationwide, as well as the leadership of pharmacy groups representing over 150 million covered lives, attended the two day meeting. JMF was asked to develop an early warning system software program matching the ICD-9 codes to the 10 Warning Signs and Physician Algorithm. This software, known as SPIRIT, is now in development and will be piloted with National managed care carriers during 2009. The software protocol is being developed by JMF and its Medical Advisory Board, and the technology will be produced by Xcenda, a division of AmeriSource Bergen Corporation. Besides the listing of the ICD-9 codes, the program assigns relative weights for each code, identifies each code as a chronic or acute condition, and provides specific exclusion criteria.

### **Summary**

Mr. Chairman, I hope you will agree that the many programs run by the Jeffrey Modell Foundation are a “perfect fit” with the announced approach to reforming healthcare articulated by the President and currently being addressed by this Congress. Specifically we have focused our attention on:

- 1.) **Prevention** through physician education and public awareness.
- 2.) **Quality of care** through the JMF Network of specialized centers.
- 3.) **Control of healthcare costs** through early diagnosis and Newborn Screening.

- 4.) **Use of technology to streamline records and generate electronic data** though new software developed by JMF for third party payers.

For FY10, we bring you what we consider to be a very modest agenda:

- 1.) We ask for **no new appropriations or programs from the subcommittee.**
- 2.) We ask for **continuation of the successful programs that we are now operating.**
- 3.) We ask for government **encouragement** and **support** for these programs.

**In exchange, we can assure you that we will continue to contribute our own funds** to every program with which we are involved. We will continue to operate these programs by fully exercising good management and ever-cognizant of our responsibilities to this committee and to the taxpayers who have supplied the funds that you pass on to us.

Mr. Chairman, we are at a critical time in our nation's healthcare history. The Jeffrey Modell Foundation is proud of the contributions we have made to the healthcare system and look forward to continuing to work with you and with all members of Congress to continue to serve the American people.

Thank you.



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LIONS WORLD SERVICES FOR THE BLIND

STATEMENT  
OF  
LIONS WORLD SERVICES FOR THE BLIND

PRESENT  
TO  
THE UNITED STATES HOUSE OF REPRESENTATIVES  
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES

BY  
RAMONA SANGALLI  
PRESIDENT AND CHIEF EXECUTIVE OFFICER  
(501-664-2743; [rsangalli@lwsb.org](mailto:rsangalli@lwsb.org))

WASHINGTON, DC  
MAY 1, 2009

Mr. Chairman, my name is Ramona Sangalli and I am the President and CEO of the Lions World Services for the Blind in Little Rock, Arkansas (LWSB). LWSB is a comprehensive rehabilitation center for people who are blind and visually impaired and has served individuals from 50 states and 58 other nations. In 2007-2008, for example, LWSB served 227 people from 31 states and 2 other countries. Each year we have a 90% success rate in placing our vocational program graduates in employment.

Thank you for giving Lions World Services for the Blind the opportunity to submit testimony to the Labor, Health and Human Services Appropriations Subcommittee with regard to funding priorities for FY 2010 appropriations. The purpose of this testimony is to provide a discussion and funding recommendations for several programs that are vital to people with vision loss so that these Americans can live independently and find gainful employment. As the Lions World Services for the Blind is also in the process of expanding its facility and building a new campus in Little Rock, Arkansas, this testimony also provides an opportunity for LWSB to inform the Subcommittee on these exciting plans.

Lions World Services for the Blind was first incorporated as Arkansas Enterprises for the Blind and since opening our doors as a rehabilitation center in March, 1947, LWSB has helped build a "new life" for more than 9,300 people. The purpose of LWSB programs are to provide personal adjustment training, psychological testing and counseling, prevocational evaluation and vocational training to individuals who are blind or visually impaired. LWSB has numerous training areas-education services, independent living and orientation and mobility-in its comprehensive personal adjustment program. The 13 vocational courses prepare people for job opportunities in the business world and for more than 40 years LWSB has operated a joint venture with the Internal Revenue Service training people with vision loss for employment at IRS call centers.

#### **Department of Labor: Office of Disability Employment Policy**

Mr. Chairman, the mission of the Office of Disability Employment Policy (ODEP) within the Department of Labor is to provide policy guidance and leadership to eliminate employment barriers for individuals with disabilities. Funding for this important office permits the Department of Labor to focus on policy analyses, technical assistance and the dissemination of effective practices that increase the employment opportunities for people with disabilities. ODEP traditionally also receives funds for a competitive grant program focused on best practices to ensure access and improve the outcome of employment and training services for disabled Americans.

Mr. Chairman, in FY 2009 ODEP received a funding level of \$26.7 million or same as the FY 2008 funding level. LWSB would recommend a funding level in FY 2010 for ODEP of \$29 million or an amount necessary to adjust for inflation and provide for program growth to meet the needs of disabled Americans. LWSB would also urge the Subcommittee to request an Action Plan from ODEP on its plans, efforts and milestones for reversing the high unemployment rate of disabled Americans.

**Department of Health and Humans Services**  
**Health Resources and Services Administration: Health Facilities**  
**Construction Account**

Mr. Chairman, the current LWSB campus includes two dormitory buildings---one for men and one for women---and four other buildings for training and administration all built in the 1960s. The last major campus expansion was completed in 1977 or 32 years ago and the limitations of the current aging and cramped facilities have been presenting increasing programmatic and operational constraints.

The LWSB Board has determined that the limitations of the current facility and location is best remedied by building a new campus with state of the art equipment and technology while also allowing a 50% increase in residential capacity to help meet national and world wide demand for LWSB services. The current LWSB campus is bordered on all sides by a residential neighborhood which sharply limits the opportunity for expansion and improvement.

Construction of the new campus will be an important component of the city's downtown revitalization and will provide substantial stimulus for the distressed economy of the area and the Nation. The new campus will be located on a hill on one of the highest points in downtown Little Rock and will cover a 6 block area with easy access off interstate 30 and 10 minutes from the Little Rock International Airport in a convenient downtown location.

Mr. Chairman, to accelerate the construction of the new campus, \$650,000 is requested from the Health Resources and Services Administration's Construction Program to finalize the design and engineering work for the new facilities needed to jumpstart and leverage private fundraising opportunities. LWSB is committed to raising the balance of the \$31 million estimated cost of the project from private sources.

**Department of Education**  
**The National Institute on Disability and Rehabilitation Research: Vocational**  
**Rehabilitation State Grants**

Mr. Chairman, as you know the vocational rehabilitation state grants program supports basic vocational rehabilitation services through formula grants to the states. These grants support a wide range of services designed to help persons with physical and mental disabilities prepare for gainful employment to the extent of their abilities. While at least 85% of the funds are allocated to local education agencies, states may reserve and use up to 10% for other related priorities including providing services for special populations.

Mr. Chairman, Lions World Services for the Blind is one of the numerous institutions around the country that access and use vocational rehabilitation state grant funds. LWSB uses these funds to support students enrolled in LWSB programs. We believe that the LWSB programs which have a very high success rate in training and helping find

employment for Americans with vision loss is one example of the effective and meritorious use of vocational rehabilitation state grant funds.

Mr. Chairman, in FY 2009 the Committee provided \$2,974,635,000 for the vocational rehabilitation state grant program. This was \$100,592,000 above the FY 2008 funding level and included the necessary funding for providing the mandatory cost of living adjustments. LWSB recommends \$3.2 billion for FY 2010 for the vocational rehabilitation state grant program, an amount needed to fund the mandatory cost of living adjustments and to also provide an inflation adjustment for the overall program.

### **Conclusion**

Tragically, nearly 70% of people who are blind or visually impaired are jobless. LWSB programs address this issue with a rich array of vocational training programs resulting in the successful employment of over 90% of LWSB vocational program graduates. The success of the LWSB programs have been recognized by the Internal Revenue Service which began a relationship with LWSB in 1967 to train and employ LWSB graduates to work as Taxpayer Services Representatives in IRS Call Centers.

LWSB is a one of a kind comprehensive residential rehabilitation program for the blind which serves people with vision loss from across the nation and the world. Since the inception of the LWSB program it has served over 9,300 individuals from all 50 states and 58 other nations.

LWSB's purpose is to provide personal adjustment training, psychological testing and counseling, prevocational evaluation and vocational training to individuals who are blind or visually impaired. LWSB has numerous training areas- educational services, independent living and orientation and mobility- in its comprehensive personal adjustment program. The 13 vocational courses prepare people for job opportunities in the business world. LWSB is financed by the tuition paid by state rehabilitation agencies that purchase training services from LWSB for their clients, by financial support of the Lions of Arkansas and surrounding states, grants, and by public donations.

### **Summary**

In summary Mr. Chairman, we would urge the Subcommittee to provide the following funding in FY 2010:

- Department of Labor- Office of Disability Employment Policy: \$29 million;
- HRSA Construction Program: \$650,000 for the design of the LWSB new campus; and
- Department of Education- Vocational Rehabilitation State Grants: \$3.2 billion.

Dr. Marina L. Weiss, Senior Vice President Public Policy and Government Affairs

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Testimony on Behalf of **March of Dimes Foundation**

Committee on Appropriations - Subcommittee on Labor, Health and Human Services and Education

The 3 million volunteers and 1,400 staff members of the March of Dimes Foundation appreciate the opportunity to submit the Foundation's federal funding recommendations for Fiscal Year 2010 (FY10). The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to support research and services related to polio. Today, the Foundation works to improve the health of women, infants and children by preventing birth defects, premature birth and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 51 chapters in every state, the District of Columbia, and Puerto Rico. Additionally, in 1998, March of Dimes established its Global Programs to extend its mission overseas through partnerships with countries to deliver interventions directed at reducing birth defects and preterm birth.

We recognize the essential investments made in the American Recovery and Reinvestment and FY09 Omnibus Appropriations Acts, and thank Congress for their support for improving the health of women, infants and children. We urge you to maintain that commitment in FY10.

#### **Preterm Birth**

Preliminary 2007 data from the National Center for Health Statistics indicate that the rate of preterm births (less than 37 weeks gestation) declined by a small but statistically significant proportion: from 12.8 to 12.7 percent. Overall, however, the incidence of preterm births has increased by 36 percent since 1981, and each year more than 540,000 infants are born too soon.

Preterm birth is a serious health problem that, according to the Institute of Medicine, cost the United States more than \$26 billion in 2005, with costs continuing to climb each year. Prematurity is the leading cause of newborn death and one in five infants who survives suffers long-term health consequences, including respiratory problems, mental retardation, developmental delays and more. Additionally, there are persistent disparities in preterm birth rates among different racial and ethnic groups: During 2003-2005 in the United States, preterm birth rates were highest for black infants (17.8%), followed by Native Americans (13.7%), whites (11.6%) and Asians (10.6%). Moreover, any woman can experience a preterm delivery but the causes remain unknown in about a half of the cases.

In June of 2008, the U.S. Surgeon General sponsored a conference to develop a research agenda for addressing the growing, costly and serious problem of preterm birth. More than 200 of the country's foremost researchers, representing a diversity of backgrounds and expertise, met for two days and created an action plan for going forward. Several cross-cutting themes emerged from this conference including recommendations to enhance biomedical and epidemiological research and to strengthen our nation's vital statistics program. The March of Dimes funding requests enumerated below are based on the recommendations of the Surgeon General's Conference.

#### **National Institutes of Health - Office of the Director**

The March of Dimes commends members of the Committee for supporting the next phase of the National Children's Study (NCS) by including \$192.3 million in the FY09 Omnibus Appropriations Act. **The Foundation urges the Subcommittee to maintain its support for this vital study in the Office of the Director's FY10 budget, by providing at least \$192 million.** In 2009, the NCS began enrolling women contemplating pregnancy and women who are pregnant in the study pilot phase enabling investigators to evaluate the overall recruitment procedures and sampling methods before the full study begins. The initial phases of the NCS will provide information concerning disorders of birth and infancy including preterm birth and its health consequences.

#### ***Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)***

**The March of Dimes recommends a funding increase of at least 7% for NICHD in FY10.** The Foundation encourages the Committee to increase funding for NICHD to enhance research directed toward improving our understanding of the factors that result in premature birth and to develop strategies for prolonging pregnancy so that infants are born full-term. A key strategy recommended by the Institute of Medicine and experts convened for the Surgeon General's conference is to create integrated transdisciplinary research centers to build the knowledge base needed for development of effective interventions to prevent prematurity. These new centers would serve as a national resource for investigators to design new research approaches and strategies to address the serious and growing problem of preterm birth.

#### **Centers for Disease Control and Prevention - Preterm Birth**

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health. **The March of Dimes recommends a \$6 million increase in the preterm birth line as authorized in the PREEMIE Act (P.L. 109-450). Funds would support expansion of epidemiological work to evaluate the social, biological, and medical factors associated with preterm birth and the reasons for disparities between racial and ethnic groups.** Currently, CDC is partnering with a number of universities and organizations to address three priorities: (1) preventing preterm birth; (2) finding the causes and evaluating the consequences of late-preterm birth; and (3) improving accuracy of key data such as gestational age.

#### **Centers for Disease Control and Prevention - National Center for Health Statistics**

National Center on Health Statistics (NCHS) national vital statistics program collects birth data which is used to monitor the nation's health status, to set priorities, and to evaluate health programs. Less than half the states are using the revised 2003 birth certificate or collecting data electronically, and without additional financial resources to help move states to the new electronic format, NCHS has indicated it will be forced to narrow the list of data collected to a "core" set of birth and death related elements (e.g., place of residence, age of mother, race of parents, and gender). As a result, nearly all data used to monitor maternal and infant health – including the use of prenatal care, smoking during pregnancy, medical risk factors, and educational attainment of parents – would be lost. Should this occur, the scope of national data on maternity and infant health status would be vastly reduced, making it exceedingly difficult to



track the health status of women, infants and children. **The March of Dimes supports a funding level of \$137.5 million for NCHS core programs and a bolus of \$15 million in each of two years to enable the Center to support states and territories as they work to implement the 2003 directive concerning electronic birth certificates.** This request reflects the recommendation of the experts convened at the 2008 Surgeon General's conference who called for, "A robust and comprehensive national vital data system.....for better evaluation of the impact of prematurity on health. This system must include full utilization of the electronic birth certificate with common data elements and definitions among states and assurance of excellent data quality and consistency."

#### **Health Resources and Services Administration - Healthy Start**

The Healthy Start Initiative is a collection of community-based projects focused on reducing infant mortality, low birthweight and racial disparities in perinatal outcomes. **The March of Dimes strongly supports Healthy Start and recommends a funding level for these projects of \$120 million in FY10.** Communities with Healthy Start programs have seen significant improvements in health outcomes.

#### **Birth Defects**

An estimated 120,000 infants in the U.S. are born with birth defects each year. Either genetic and environmental factors, or a combination, can cause a birth defect. However, the causes of 70 percent of birth defects remain unknown. Investing additional federal resources into research to unveil the causes and prevent the incidence or reduce the incidence of birth defects is sorely needed.

#### **CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD)**

The NCBDDD conducts programs to protect and improve the health of children by preventing birth defects and developmental disabilities and by promoting optimal development and wellness among children with disabilities. For FY10, the March of Dimes requests an **increase of \$4.5 million to support birth defects research and surveillance and an additional \$2 million for folic acid education.**

Sustaining the investment in the National Birth Defects Prevention Study—the largest case controlled study of birth defects ever conducted—is needed to unveil the causes and point the way toward strategies for preventing birth defects. In 2008, researchers found that a correlation exists among infants conceived with assistive reproductive technology and increased risk for certain birth defects. Additionally, data from this study shows that women who develop diabetes before becoming pregnant are more likely to have a child with one or more birth defects.

NCBDDD also supports state-based birth defects tracking systems and programs to prevent and treat affected children. Surveillance forms the backbone of a vital, functional, and responsive public health network. Without additional funding, CDC indicates that it will be forced to reduce from 15 to 12 the number of states receiving support in FY10.

Finally, NCBDDD is conducting a national public and health professions education campaign with the goal of increasing the number of women consuming appropriate amounts of folic acid. Unfortunately, according to a recent CDC study only 21 percent of Hispanic women are consuming the recommended amount of folic acid, compared with over 40 percent of white

women. With additional funding, the Center will be able to reach more women and to focus particular attention on Hispanic communities where rates of neural tube defects are highest.

#### **Newborn Screening**

Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal, and functional disorders in newborns. Screening detects conditions in newborns that, if left untreated, can cause disability, mental retardation, serious illness, or even death. For more than 40 years, states have operated programs through which the 4 million babies born each year in the United States are screened. While significant progress has been made in recent years assuring that all states screen for a core set of conditions, ongoing disparities among state programs mean that too many infants with serious birth defects are not being diagnosed and treated in time to avoid some tragic consequences. In 2008, Congress recognized the need for additional resources dedicated to newborn screening by unanimously approving the Newborn Screening Saves Lives Act (P.L. 110-204).

#### **Health Resources and Services Administration (HRSA)**

The Foundation urges Congress to provide **\$30 million in funding, as authorized by P.L. 110-204, for the HRSA heritable disorders program** in support of state efforts to improve programs, to acquire innovative testing technologies, and to increase capacity to reach and educate health professionals and parents on newborn screening programs and follow-up services.

#### **Other**

##### **Agency for Health Research and Quality (AHRQ)**

AHRQ supports research to improve health care quality, reduce costs and broaden access to essential health services. **The Foundation recommends \$405 million** for AHRQ to continue its important work and support initiatives such as the development of pediatric quality measures and comparative effectiveness research.

##### **Health Resources and Services Administration - Maternal and Child Health Block Grant**

Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant, supports a growing number of community-based programs (i.e., home visiting, respite care for children with special health care needs, and supplementary services for pregnant women and children enrolled in Medicaid and the State Children's Health Insurance Program), but federal support has not kept pace with increased enrollment and demand for services. **The March of Dimes recommends fully funding the MCH Block Grant at the authorized level of \$850 million.**

##### **CDC National Immunization Program**

Infants are particularly vulnerable to infectious diseases, which is why it is critical to protect them through immunization. CDC has found that, each day, nearly 12,000 babies are born in the U.S. who will need to be immunized against 14 vaccine-preventable diseases before age two. The CDC National Immunization Program supports states, communities, and territorial public health agencies through grants to reduce the incidence of disability and death resulting from vaccine-preventable diseases. The March of Dimes **recommends \$800 million** and urges the subcommittee to continue its longstanding policy of ensuring that federal vaccine programs are well-funded.

##### **CDC Polio Eradication**

Since its creation as an organization dedicated to research and services related to polio, the March of Dimes has been committed to the eradication of this disabling disease. For FY10, the Foundation recommends a funding level of \$102 million for the CDC global polio eradication program. Level with FY09, this funding would allow CDC to continue its supplementary immunization activities in the remaining endemic and high-risk countries in Africa and Asia and to move quickly to interrupt polio transmission in these regions.

**MARCH OF DIMES  
FY2010 FEDERAL FUNDING PRIORITIES  
(Dollars in Millions)**

<b>PROGRAM</b>	<b>FY 2009 FUNDING</b>	<b>MARCH OF DIMES REC</b>
<b>National Institutes of Health (Total)</b>	30,317	32,439
National Children's Study	192.3	192
Common Fund	541	579
National Institute of Child Health and Human Development	1,294	1,385
National Human Genome Research Institute	503	538
National Center on Minority Health and Disparities	206	220
<b>Centers for Disease Control and Prevention (Total)</b>	6,670	8,600
Birth Defects Research & Surveillance	21.123	25.623
Folic Acid Campaign	2.8	4.8
Immunization	496	800
Polio Eradication	102	102
Preterm Birth	2	8
National Center for Health Statistics	125	152.5
<b>Health Resources and Services Administration (Total)</b>	7,259	8,500
Maternal and Child Health Block Grant	662	850
Newborn Screening	10	30
Newborn Hearing Screening	19	19
Consolidated (Community) Health Centers	2,190	2,313
Healthy Start	102	120
<b>Agency for Healthcare Research and Quality</b>	373	405

STATEMENT BY THE MENDED HEARTS, INCORPORATED  
ROBERT A. SCOTT, NATIONAL ADVOCACY CHAIRMAN  
bobscorecks@yahoo.com  
(401)766-0483  
FY 2010 APPROPRIATIONS FOR LABOR-HHS-EDUCATION

I am Robert A. Scott, National Advocacy Chairman for Mended Hearts Inc., a heart disease support group with more than 300 chapters across the United States and Canada. In 2008, accredited Mended Hearts volunteers visited about 3,000 heart patients in more than 400 hospitals throughout the United States.

As a walking testimony of the benefits of NIH-supported heart research, I would like to share my story. In 1998, at age forty-eight, I suffered my first heart attack while playing volleyball. While at Woonsocket, Rhode Island's Landmark Medical Center, doctors diagnosed me as suffering a so called silent heart attack. I learned that as many as 4 million Americans experience this type of episode—a heart attack with no warning.

After being stabilized, I was transferred to Roger Williams Hospital, in Providence, Rhode Island for a heart catheterization—the gold standard for diagnosis of heart problems. The procedure showed that I had a blockage in my artery that required a stent to open it. Also, it showed that the lower chamber of my heart was damaged, resulting in congestive heart failure that could be controlled with medicine. A stent was inserted in my artery in Rhode Island Hospital.

In 1999, I received another heart catheterization in Miriam Hospital because of the damage to my heart from the silent heart attack. However, this time, I was told that my artery could not be repaired with a stent and that I needed heart bypass surgery the next morning. Calling me a high risk patient because of my age and my weakened heart, my surgeon encouraged me to find a doctor in Boston because my heart might not start again. However, he assured me that if this happens they had a device that could keep me alive for only seven hours. Thank goodness, he told me that in Boston they had another device that could keep me alive for seven months while they located a replacement heart. In less than ten hours, I went from the possibility of needing another stent, heart bypass surgery, and a heart transplant. My journey with heart disease continued.

My next stop was to visit my local cardiologist in Woonsocket who estimated my survival rate at 20%, but he thought I would survive the heart bypass surgery. Thankfully, he was right and I survived heart bypass surgery.

But my journey didn't end there. My congestive heart failure was causing my heart to beat irregularly, so an implantable defibrillator was inserted to control the problem in 2002. However, this device had to be replaced nearly four years later. My story continues in 2007 where I started experiencing daily chest pain and shortness of breath. Yet another heart catheterization showed that I needed an additional stent, but this time in Miriam Hospital. After the procedure, the doctor told me the original heart bypass surgery was no longer effective. Although I was scared, my doctors comforted me by explaining that a new medical

innovation could save my life—a drug eluting stent. They explained that it could open up the original blockage from my silent heart attack. My doctor explained that if these state-of-the art stents had been available in 1998, I would not have had to have heart bypass surgery.

Today, heart attack, stroke and other cardiovascular diseases remain our Nation's most costly and No. 1 killer and a major cause of disability. Thanks to medical research supported by the NIH, I am alive today. I am concerned that NIH continues to invest only 4% of its budget on heart research and a mere 1% on stroke research when there are so many people in our country just like I am. Enhanced NIH funding dedicated to heart and stroke research will bring us closer to a cure for these often deadly and disabling diseases.

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**TESTIMONY FOR THE FISCAL YEAR 2010 PUBLIC WITNESS RECORD**  
**House Committee on Appropriations Subcommittee on Labor, Health & Human**  
**Services, Education, and Related Agencies**

*"It must not for a moment be forgotten that the core of any social plan must be the child."*

*-President Franklin Roosevelt*

*US Committee on Economic Security, Report to the President, 1935*

Congressman Obey and Distinguished Members of the Subcommittee: Mentor Consulting Group is pleased to submit testimony for the Public Witness Record to ask the Subcommittee to direct its attention to the President's Fiscal Year 2010 proposed budget recommendation calling for the elimination of the U.S. Department of Education's (ED) Mentoring Program. **Mentor Consulting Group (MCG) is seeking your help in restoring the funding for this important and much needed program to enable agencies from Rhinelander, Wisconsin to Los Angeles, California, from Lawrence, Kansas to the Bronx, to continue supporting match relationships for a third year.**

**It is our understanding that the cost of restoring the third year of funding for 2008 Mentoring Program grantees is estimated at \$17 million.**

Mentoring is fundamentally predicated on creating healthy and meaningful relationships for youngsters who are in jeopardized circumstances with respect to their potential for achieving long-term educational and socio-emotional success. **Research demonstrates that youth who successfully transition from risk-filled backgrounds to responsible adulthood are consistently distinguished by the presence of a caring adult in their lives. Prematurely ending matches, such as those that have been recently established through the Mentoring Program grants, can be potentially harmful to mentees.** MCG strongly urges the Subcommittee to prevent this possibility from turning into a tragic reality for thousands of vulnerable children.

The ED Mentoring Program, authorized under the No Child Left Behind Act (NCLB) of 2002, Section 4130, is a competitive federal grant program managed by the Office of Safe and Drug Free Schools (OSDFS). It addresses the lack of supportive adults at critical turning points in the lives of youngsters in grades 4-8. The funding supports mentoring programs operating in local education agencies (LEAs); nonprofit community- and faith-based organizations; and partnerships between LEAs and local non-profits. Funded programs are designed to:

- a) improve interpersonal relationships with peers, teachers, family members and other adults;
- b) increase personal responsibility and community involvement; discourage the use of drugs and alcohol;
- c) discourage the use of weapons;
- d) reduce delinquency;
- e) improve academic achievement; and,
- f) reduce school dropout.

**Since 2004, MCG has worked on-site with 57 ED Mentoring Program** grantees serving in the capacity of overall technical assistance provider, e.g., mentor/mentee training, mentor recruitment, marketing, sustainability planning and/or as the external evaluator. Our client sample is rich with diversity both with respect to the size and scope of their grants, e.g., we work with the agency receiving the smallest of the 2008 awards, as well as their experience in operating a formal mentoring program. Another of our clients, also a 2008 grantee, is among the thirty largest school districts in Texas and is working with seventeen partnering school campuses. **This grantee exceeded their one-to-one match goal of 150 matches before the end of the first year of the grant.** The potential impact on 150 youngsters, in this one community alone, should this program be eliminated, is unimaginable.

**A key “lesson learned” based on our experience with all of these clients is that the complexities of operating a mentoring program cannot be overstated. Building safe and secure relationships between youngsters and caring adults requires the attention and involvement of trained, committed, and competent staff who understand the quality assurance standards of the mentoring field.**

Beyond the potential benefits for the youth, the ED Mentoring Program has enabled grantees to forge strategic community partnerships between concerned citizens and multiple youth serving organizations to maximize the use of community resources. Also negatively affected by this proposed termination of funds are those staff hired to work with the ED mentoring program who have worked diligently over the past 13 months to introduce and promote these programs in their community and to build these vital new mentor/mentee relationships. **Premature termination of this grant program would, of course, force layoffs in 110 communities across the country. By contrast, the economic stimulus package is working hard to counter just such layoffs!**

**Research over the past decade has demonstrated that mentoring is a viable intervention strategy that holds considerable promise.** Studies of structured mentoring programs, including those that have received federal funding, suggest that **the programs are likely to be more successful when they include a strong infrastructure and facilitate caring relationships.** Infrastructure refers to a number of activities including identifying the youth population to be served and the activities to be undertaken, screening and training mentors, supporting and supervising mentoring relationships, collecting data on youth outcomes, and creating strategies for long-term sustainability. (Ref. Jean Balwin Grossman, ed., *Contemporary Issues in Mentoring, Public/Private Ventures*, p.6). **The ED Mentoring Program is providing much needed funding to ensure the integrity of the requisite infrastructure and facilitation of caring relationships in programs that would otherwise be severely marginalized.**

Another signal research finding is that **mentoring relationships are likely to promote positive outcomes for youth and avoid harm when they are close, consistent, and enduring.** (Ref. Rhodes and DuBois, "Understanding and Facilitating the Youth Mentoring Movement," p. 9). Closeness is the bond that is created between the youth and mentor. The characteristics of the volunteer mentors (no mentors in ED Mentoring Program matches are able to be remunerated) have also proven to be important in shaping the relationships and strengthening the bond. For example, individuals with prior experience in helping roles or occupations, an ability to understand and respect cultural differences, and an overall sense of commitment to mentoring all appear to contribute positively to the relationship and overall match quality. Further, it appears that **relationships may be especially beneficial when they remain part of the youth's life for multiple years** (Klaw, Fitzgerald & Rhodes, 2003; McLearn et al., 1998) **and have the opportunity to facilitate adaptation throughout significant portions of their development** (DuBois & Silverthorn, 2005b; Werner, 1995). **These findings are of particular importance to the 4<sup>th</sup> through 8<sup>th</sup> grade population served by the ED Mentoring Program.**

The ED Mentoring Program garnered national attention recently following publication of the *Impact Evaluation of the U.S. Department of Education's Student Mentoring Program* report prepared by Abt Associates for the Institute of Education Sciences (March 2009). ED contracted with Abt in 2005 to conduct the study which used an experimental design in which students were randomly assigned to a treatment or control group. The study involved thirty-two ED Mentoring Program grantee sites that were funded beginning in 2004 or 2005. Grantees selected for participation in the Impact Study were required to meet three criteria:

- Be operational so that it could recruit and match students to mentors in the fall of 2005 for the first group of grantees and Fall 2006 for the second group;
- Able to over-subscribe or identify excess demand supporting experimental study needs for an *un-served* control group (i.e., able to provide tangible evidence of a pool of 4<sup>th</sup> through 8<sup>th</sup>



grade students referred to the mentoring program) of adequate size to support study requirements; and

- Willing and able to cooperate with the data collection and logistical needs of the national evaluation, including random assignment.

While the findings of the *Impact Evaluation* study are indeed mixed, **MCG is encouraged that this study has captured several of the inherent challenges that often confront early cohorts of federally funded mentoring initiatives.** This study contributes to the growing body of research evidence, however, the field warrants additional comparative evaluation studies that look at different program models. Each and every cohort of a federally funded initiative should be evaluated and this study helps to make that very point. **More recently funded ED Mentoring Program grantees, including those in 2008, have had the benefit of an expanded comprehensive technical assistance package that includes conference trainings, webinars, resource materials (available online), and site visits designed to help program coordinators with all aspects of program implementation, data tracking, and operation. In addition, grantees are now trained on specific aspects of program sustainability.**

In closing, we would like to share with you a comment from a mentee who met with us during a recent site visit. When asked what having a mentor meant to him, Isaiah, a fourth grade student replied, **“Having a mentor has been the best thing that has happened to me in my whole life.”**

MCG fully acknowledges and appreciates the widespread economic and social challenges facing our country at this time. However, **reinstatement of the ED Mentoring Program funding in the 2010 budget is a clarion call for moral policymaking. That call is befitting of your role as members of this august body and will ensure that youngsters like Isaiah will one day achieve their full potential and enjoy their opportunity to sit as a distinguished member of Congress.**

Thank you for the opportunity to submit this testimony.

STATEMENT BY THE MONTGOMERY COUNTY STROKE ASSOCIATION  
 FLORA INGENHOUSZ, LCSW  
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 FY 2010 APPROPRIATIONS FOR LABOR-HHS-EDUCATION  
 NATIONAL INSTITUTES OF HEALTH (NIH)

I am Flora Ingenhouz, a psychotherapist in private practice in Silver Spring, Maryland. I have always been in excellent health and live an active, healthy lifestyle. Doctors always commented on my low blood pressure and my excellent cholesterol numbers. But I suffered a stroke three years ago. It was a shock to me and my family, friends and clients.

One morning three years ago, when doing a load of laundry, I had no idea how to set the dials, despite the fact that I had used them weekly for the last ten years. I stood there for what seemed an eternity before I figured out how to set the dials.

Next I went to do yoga. In one of the poses, I noticed my right arm was hanging limp. When my husband asked me a question, my answer was just the opposite of what I wanted to say. I caught my error and tried again, but it soon became clear that something was wrong. My symptoms kept getting worse.

When we walked into the ER, my right leg was weak, and I could not sign my name at the desk. Twelve hours later, I could not move my right side, and my speech was reduced to yes and no. Not a good thing for a psychotherapist, where language is a primary tool!

In the ER, a CT scan showed a hemorrhagic or bleeding stroke where an artery burst, destroying millions of brain cells within minutes, affecting my speech and my ability to perform activities like dressing in the correct order. Also, my right arm and leg were extremely weak. However, I could understand everything, and I was never completely paralyzed. But, I was scared.

I was in intensive care for four days of observation and lots of testing, but the tests provided no answers. Two days after my stroke, while still in intensive care, I started occupational, physical and speech therapy. It was extremely challenging to feed myself with my right hand, requiring all my concentration. After a meal or brushing my teeth, I was exhausted. Speaking was the hardest of all. My brain seemed devoid of words.

After being stabilized, I was transferred to the National Rehabilitation Hospital. For a week, I endured speech, physical, occupational and recreational therapies.

Speech therapy was the hardest, but also the most important given my profession. Several times, the speech therapist challenged me to the brink of tears.

After a week at the Rehabilitation Hospital, I went home and to outpatient therapies. Speech therapy lasted the longest. After being discharged from speech therapy, I still had deficits in my organizational skills and abstract thinking.

As I struggled with starting to see my clients again, I slid into a deep depression. I was not confident that I could continue to practice. For months, I saw no point in living. Recovery from my post-stroke depression was harder than the recovery of my arms and legs and even speech!

Being a psycho-therapist, I know how to treat depression, so I went to a psychiatrist who prescribed anti-depressant medication and, I also found a psychotherapist.

After months on anti-depressants and excellent psychotherapy, my depression began to lift. I continue on the drugs and to see my psychotherapist. Emotionally, the aftermath of my stroke cut deep.

I am fortunate that three years post-stroke, I am back to my practice full-time. I lead support groups for stroke survivors and caregivers through the Montgomery County Stroke Association and served on its Board. I now lecture on stroke, stroke prevention and stroke recovery. I founded "hope for stroke"--individual and family counseling for stroke survivors and caregivers. And I have developed, together with a colleague, a seminar for professionals in the stroke field on the role of mental health providers in stroke recovery. In addition, I have participated in a NIH study about stroke recovery.

Once again, I am in excellent health and have resumed my active life style. I thank my brain for having the capacity to work around the dead cells. But most of all, I thank my therapists for my recovery. Their ability to zero in so effectively would not have been possible without NIH research.

Because stroke is a leading cause of death and disability and major cost to society, I urge you to provide stroke research with a significant funding increase. I am concerned that NIH continues to invest only 1 percent of its budget in stroke research.

Thank you.



**NAEVR**

National Alliance For  
Eye And Vision Research

*Serving as Friends of the National Eye Institute*

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[ABOUT NAEVR APPEARS ON THE LAST PAGE]

**WRITTEN TESTIMONY IN SUPPORT OF INCREASED  
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)  
AND THE NATIONAL EYE INSTITUTE (NEI)  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED  
AGENCIES SUBCOMMITTEE OF THE U.S. HOUSE OF REPRESENTATIVES  
COMMITTEE ON APPROPRIATIONS  
April 6, 2009**

**EXECUTIVE SUMMARY**

**NAEVR requests a Fiscal Year (FY) 2010 NIH funding increase of at least seven percent, to a level of \$32.4 billion, which represents a modest three percent increase plus the biomedical inflation rate, estimated at 3.8 percent in FY2009. This increase is necessary to keep pace with inflation and rebuild the base, since NIH has lost 14% of its purchasing power during the past six funding cycles.** NAEVR commends the Congressional leadership's actions in FY2008 and 2009 to increase NIH funding, including the \$150 million in the FY2008 supplemental dedicated to investigator-initiated grants, the \$10.4 billion in two-year stimulative NIH funding within the American Recovery and Reinvestment Act (ARRA), and the final FY2009 appropriations inflationary increase of 3.2 percent. However, NIH needs sustained and predictable funding to rebuild its base and support multi-year investigator-initiated research, which is the cornerstone of the biomedical enterprise. Annual increases of at least seven percent put NIH on a pathway to budget-doubling within the next ten years. Secure and consistent funding for biomedical research is integral to the nation's economic and global competitiveness. NIH is a world-leading institution that must be adequately funded so that its research can reduce healthcare costs, increase productivity, and save and improve the quality of lives.

**NAEVR requests that Congress make vision health a top priority by increasing NEI funding by at least 7 percent, to a level of \$736 million, in this year that NEI celebrates its 40<sup>th</sup> anniversary. Over the past six funding cycles, NEI lost 18 percent of its purchasing power.** Despite funding challenges, NEI has maintained its impressive record of breakthroughs in basic and clinical research that have resulted in treatments and therapies to save and restore vision and prevent eye disease. NEI will be challenged further, as 2010 begins the decade in which more than half of the 78 million Baby Boomers will turn 65 and be at greatest risk for developing aging eye disease. Adequately funding the NEI is a cost-effective investment in our nation's health, as it can delay, save, and prevent expenditures, especially to the Medicare and Medicaid programs.

**FY2010 FUNDING AT \$736 MILLION ENABLES NEI TO EXPAND ITS IMPRESSIVE  
RECORD OF BASIC AND CLINICAL COLLABORATIVE RESEARCH THAT HAS  
RESULTED IN TREATMENTS AND THERAPIES TO SAVE AND RESTORE VISION  
AND PREVENT EYE DISEASE**

Immediately after President Obama signed the ARRA, Acting NIH Director Raynard Kington, M.D., Ph.D., identified the major health challenges that NIH faces, especially when describing the potential emphasis of the newly created "Challenge Grants": the shift from acute to chronic diseases, and the attendant co-morbid conditions; an aging population; health disparities; and prevention. Since its creation 40 years ago, the NEI has been directly addressing these issues as they apply to vision and has been a leader in what former NIH Director Elias Zerhouni, M.D., has described as the 21<sup>st</sup> century paradigm for healthcare research and clinical practice, or "P4 Medicine"—that which is predictive, preemptive, personalized, and participatory.

NEI continues to be a leader in basic research—especially that which elucidates the genetic basis of ocular disease—and in translational research, as those gene discoveries can lead to development of diagnostics and treatments. NEI Director Paul Sieving, M.D., Ph.D., has reported that one-quarter of all genes identified to date through NEI's collaboration with the National Human Genome Research Institute (NHGRI) are associated with eye disease/visual impairment. Recent examples include:

- In 2005, NEI reported that gene variants of Complement Factor H (CFH), the protein product of which is engaged in the control of the body's immune response, are associated with increased risk of developing age-related macular degeneration (AMD), the leading cause of vision loss. NEI-funded researchers are now working on potential therapies, including the manufacture and use of a protective version of the CFH protein in an augmentation strategy similar to that of treating diabetes with insulin. This therapy is under development and expected to enter Phase I clinical safety trials in Summer 2009. These same researchers are also conducting research in individuals with liver transplants, since most CFH is made in the liver, to see what happens when an individual receives a different form of CHF. The researchers hope that these studies reinforce the concept of providing AMD patients with doses of the protective protein or, in the future, with gene therapy approaches that would allow the liver to produce the protein on its own. Researchers have also reported relationships between CFH and obesity, coronary artery disease, myocardial infarction, and stroke, among other conditions—the findings of which facilitate new opportunities for trans-NIH research.
- In addition to gene-based approaches to develop AMD treatments, NEI's collaborative research into factors that inhibit new blood vessel growth has in part fostered the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing and restoring vision, and NEI's Diabetic Retinopathy Clinical Research (DRCR) Network is further evaluating these drugs for treatment of

macular edema associated with diabetic retinopathy (DR). In March 2008, NEI-funded researchers announced that damage from both AMD and DR was prevented and even reversed when the protein Robo4 was activated in mouse models that simulate the two diseases. Robo4 treated and prevented the diseases by inhibiting abnormal blood vessel growth and by stabilizing blood vessels to prevent leakage. Since this research into the "Robo4 Pathway" used animal models associated with these diseases that are already used in drug development, the time required to test this approach in humans could be shortened, expediting approvals for new therapies

- In late April 2008, researchers funded by the NEI and private funding organization Foundation Fighting Blindness reported on their use of gene therapy to restore vision in young adults who were virtually blind from a severe form of the neurodegenerative disease Retinitis Pigmentosa, known as Leber Congenital Amaurosis (LCA). Seven years earlier, the researchers shared on Capitol Hill results of a preclinical study of the same gene therapy, which at the time was successfully giving vision to dogs born blind with LCA. The subsequent human gene therapy trial validated the process of putting genes in the body to restore vision. Although the primary goal of the Phase I study was to ensure patient safety, the researchers reported through both objective and subjective testing that the patients were able to read several lines on an eye chart, had better peripheral vision, and better eyesight in dimly lit settings. In further research, the investigators will treat LCA patients as young as eight years old, since they believe the most dramatic results will be seen in young children
- In late 2008, NEI initiated its new NEI Glaucoma Human genetics collaBORation, known as NEIGHBOR, through which seven U.S. research teams will lead genetic studies of the disease. Glaucoma is called the "stealth robber of vision" as it often has no symptoms until vision is lost, and anywhere from 50-75 percent of individuals with it are undiagnosed. It is also the leading cause of preventable vision loss in African American and Hispanic populations. Previously, in a March 13-14, 2008, joint *Glaucoma Endpoints* meeting with the FDA, NEI-funded researchers acknowledged that glaucoma is a complex, neurodegenerative disease in which detectable changes within the eye may not progress linearly or in concert with functional changes, that is, vision loss. All of these factors emphasize the vital nature of determining the genetic basis of this disease.

#### **FY2010 FUNDING AT \$736 MILLION ENABLES NEI TO FULLY FUND NEW INITIATIVES THAT MORE FULLY CHARACTERIZE EYE DISEASE**

NEI has been a leader in collaborative research, the use of networks to study diagnostics and treatments and their use in clinical settings, and in ocular epidemiology to characterize the nature and frequency of eye disease in diverse populations to better manage public health. In FY2008, NEI reported on/launched the initial phase of three important new programs to characterize eye disease that will require adequate future funding.

- In early 2009, the NEI and the National Aeronautics and Space Administration (NASA) reported on the use of a compact fiber optic probe developed for the space program that has proven valuable as the first non-invasive early detection device for cataracts, the leading cause of vision loss worldwide. Using a laser light technique called dynamic light scattering (DLS), which was developed to analyze the growth of protein crystals in a zero-gravity environment, the probe measures the amount of light scattering by an anti-cataract protein called alpha-crystallin. This protein binds to other proteins when they become damaged, thus preventing them from bunching together to form a cataract. Since humans are born with a fixed amount of alpha-crystallin, if it is depleted due to radiation exposure, smoking, diabetes, or other causes, a cataract can result. The probe senses protein damage due to oxidative stress, a key process involved in many medical conditions including age-related cataract and diabetes, as well as Alzheimer's and Parkinson's disease
- In late 2008, NEI launched a new research network, the Neuro-Ophthalmology Research Disease Investigator Consortium, or NORDIC. There is a broad spectrum of neuro-ophthalmic disorders that collectively affect millions of people. However, since many of the visual disorders associated with other systemic and neurologic conditions fit the definition as "rare" diseases, they have not been adequately studied. NORDIC will initially lead multi-site observational and treatment trials, involving nearly 200 community and academic practitioners, to address the risks, diagnosis, and treatment of two such "rare" diseases: idiopathic intracranial hypertension (visual dysfunction due to increased intracranial pressure) and thyroid eye disease (also called Graves' disease, in which muscles of the eye enlarge and cause bulging of the eyes, retraction of the lids, double vision, decreased vision, and irritation). The network's structure enables it to study additional conditions. The NEI and NORDIC's Principal Investigator have already begun coordinating with the Department of Defense's (DOD) newly established Vision Center of Excellence (VCE) about the applicability of NORDIC research to combat-related eye injuries, especially those associated with Traumatic Brain Injury (TBI), which is being experienced in record numbers in Iraq and Afghanistan.
- There is currently almost no information on the prevalence, risk factors, and genetic determinants in Asian Americans—one of the fastest growing racial groups in the US. Studies from East Asia have suggested that Asians have a spectrum of eye diseases different from that of White Americans, African Americans, and Hispanics. In late 2008, NEI launched the Chinese American Eye Study to characterize the extent of eye disease in Chinese Americans, the largest Asian sub-group in the US. Participants 50 years and older will be evaluated for blindness, visual impairment, and eye disease. The observations will add to the expanding body of knowledge about aging eye disease. Past NEI-funded studies have yielded dramatic findings—the Ocular Hypertension Treatment Study (OHTS) reported that African Americans have a four-fold greater risk of developing glaucoma than White Americans, and the Los Angeles

Latino Eye Study (LALES) found increased incidence of glaucoma and diabetic retinopathy in individuals of Mexican descent. All of these studies assist in developing public health policy, especially in relation to education, prevention, rehabilitation, and eye care services.

**VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT INCREASES HEALTHCARE COSTS, REDUCES PRODUCTIVITY, AND DIMINISHES QUALITY OF LIFE**

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is \$68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As recently as March 2008, the NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life.

In 2009, the NEI will celebrate its 40<sup>th</sup> anniversary as the NIH Institute that leads the nation's commitment to save and restore vision. During the next decade, more than half of the 78 million Baby Boomers will celebrate their 65th birthday and be at greatest risk for developing aging eye disease. As a result, sustained, adequate federal funding for the NEI is an especially vital investment in the health, and vision health, of our nation as the treatments and therapies emerging from research can preserve and restore vision. Adequately funding the NEI can also delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

**NAEVR urges FY2010 NIH and NEI funding at \$32.4 billion and \$736 million, respectively, reflecting an at-least seven percent increase over FY2009.**

**ABOUT NAEVR**

The National Alliance for Eye and Vision Research (NAEVR) is a 501(c)4 non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. Visit the Web site at [www.eyerresearch.org](http://www.eyerresearch.org).



**Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education Concerning Programs in the United States Departments of Labor, Health and Human Services, and Education**

By  
**The National Alliance to End Homelessness**

**Nan Roman, President**

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April 30, 2009

The National Alliance to End Homelessness (the Alliance) is a nonpartisan, nonprofit organization that has several thousand partner agencies and organizations across the country. These partners include local faith-based and community-based nonprofit organizations and public sector agencies that provide homeless people with housing and services such as substance abuse treatment, job training, and physical health and mental health care. In addition, we have supported over 200 state and local entities who have completed ten year plans to end homelessness. The Alliance represents a united effort to address the root causes of homelessness and challenge society's acceptance of homelessness as an inevitable byproduct of American life.

**Summary of Appropriations Goals**

**1. Moving Forward to End Homelessness**

Communities across America are working toward ending homelessness. Communities are using federal, state, and local funds to help homeless persons maintain housing. Especially during the current economic recession, it is important that this progress not be undermined. To this end, the Alliance recommends the following:

- Allocate \$120 million for services for people experiencing homelessness within the Programs of Regional and National Significance accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.
- Increase funding for the Projects for Assistance in Transition from Homelessness (PATH) program to \$75 million.
- Increase funding for the Runaway and Homeless Youth Act Programs to \$165 million.
- Provide \$2.602 billion in the Community Health Center program within the Health Resource Services Administration. This would result in \$226.3 million for the Health Care for the Homeless program, a \$36 million increase from FY 2009.
- Fund Education for Homeless Children and Youth services at \$210 million.
- Increase funding for the Homeless Veterans Reintegration Program to \$50 million, its authorized level.

**2. Connecting Homeless Families, Individuals, and Youth to Mainstream Services**

People experiencing homelessness also depend on mainstream programs. The Alliance recommends the following to meet this goal:

- Fund the Social Services Block Grant (SSBG) program at 2.3 billion.
- Reject cuts and fund the Community Services Block Grant (CSBG) program at \$725 million.

- Appropriate \$60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program.
- Fund the Community Mental Health Services Performance Partnership Block Grant at \$486.9, a \$66.1 million increase.
- Fund the Substance Abuse Prevention and Treatment Block Grant at \$1.929 billion, a \$150 million increase over FY 2009.

### **Background**

Our 2009 report, *Homelessness Counts: Changes in Homelessness from 2005 to 2007*, estimates that 671,859 people are homeless on any given night. This includes **248,511 persons in families and 423,348 individuals**. **Eighteen percent** of all homeless people are defined as chronically homeless; these are people who have a disability and who have been homeless repeatedly or continuously for twelve months. These numbers are based on homeless counts performed in 2007, prior to the current economic recession. Compared to 2005, there were decreases across the country resulting in a 10 percent overall decline in homelessness. Anecdotal evidence suggests there could be increases in homelessness as communities report the results of their 2009 counts. To help stave off drastic increases in homelessness, we need Congress to invest in what we know works. Successful interventions for all homeless populations couple housing with an appropriate level of services for the family or individual.

For chronically homeless populations, permanent supportive housing successfully and cost-effectively ends homelessness. These programs couple a home with intensive supportive services, such as health care, mental health services, addiction treatment, employment training, and case management.

There are also successful housing programs linked with services which are proving to be effective for all homeless populations, as well as those at risk of homelessness. The services, based on clients' need, are usually less intensive than in permanent supportive housing but are still essential for these families, individuals, and youth.

Therefore, not only does the Department of Housing and Urban Development play a role in ending homelessness, so do the Departments of Labor, Health and Human Services, and Education. **We call on Congress to adequately fund programs that assist states and local entities in developing permanent housing and the necessary social services to end homelessness for all Americans.**

### **Detailed Program Descriptions**

#### **Goal #1 - Moving Forward to End Homelessness**

#### **Support Services for Permanent Supportive Housing Projects**

*The Alliance recommends allocating \$120 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.* Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient.

### **Projects for Assistance in Transition from Homelessness (PATH)**

*The Alliance recommends that Congress increase PATH funding to \$75 million and adjust the funding formula to increase allocations for small states and territories.*

PATH provides outreach to eligible consumers and ensures that those consumers are connected with mainstream services, such as Supplemental Security Income (SSI), Medicaid, and welfare programs. Under the PATH formula grant, approximately 30 states share in the program's annual appropriations increases. The remaining states and territories receive the minimum grant of \$300,000 for states and \$50,000 for territories. These amounts have not been raised since the program was authorized in 1991. To account for inflation, the minimum allocation should be raised to \$600,000 for states and \$100,000 for territories. Amending the minimum allocation requires a legislative change. If the authorizing committees do not address this issue, we hope that appropriators will explore ways to make the change through appropriations bill language.

### **Runaway and Homeless Youth Act (RHYA) Programs**

*The Alliance recommends funding the RHYA programs at \$165 million.* RHYA programs support cost-effective, community- and faith-based organizations that protect youth from the harms of life on the streets. The RHYA programs can either reunify youth safely with family or find alternative living arrangements. RHYA programs end homelessness by engaging youth living on the street with Street Outreach Programs, quickly providing emergency shelter and family crisis counseling through the Basic Centers, or providing supportive housing that helps young people develop lifelong independent living skills through Transitional Living Programs. Recently, the Congressional Research Service issued a report complimenting the good work of RHYA programs but detailing the gaps in services due to limited funding. For example, only one-tenth of the youth who connect with a RHYA program are able to receive services. It is essential that Congress increase this program.

### **Community Health Centers and Health Care for the Homeless (HCH) Programs**

*The Alliance recommends \$2.602 billion in the Community Health Center program within Health Resource Services Administration. This would result in \$226.4 million for the HCH program, a \$36 million increase over FY 2009.* Persons living on the street suffer from health problems resulting from or exacerbated by being homeless, such as hypothermia, frostbite, and heatstroke. In addition, they often have infections of the respiratory and gastrointestinal systems, tuberculosis, vascular diseases such as leg ulcers, and hypertension.<sup>1</sup> Health care for the homeless programs are vital to prevent these conditions from becoming fatal. Congress allocates 8.7% of the Consolidated Health Centers account for HCH projects.

### **Education for Homeless Children and Youth (EHCY)**

*The Alliance recommends funding EHCY at \$210 million.* The most important potential source of stability for homeless children is school. The mission of the Education for Homeless Children and Youth program is to ensure that these children can continue to attend school and thrive. The Education for Homeless Children and Youth program, within the Department of Education's Office of Elementary and Secondary Education, removes obstacles to enrollment and retention by establishing liaisons between schools and shelters and providing funding for transportation, tutoring, school supplies, and the coordination of statewide efforts to remove barriers.

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<sup>1</sup> Harris, Shirley N, Carol T. Mowbray and Andrea Solarz. *Physical Health, Mental Health and Substance Abuse Problems of Shelter Users*. Health and Social Work, Vol. 19, 1994

### **Homeless Veterans Reintegration Program (HVRP)**

*The Alliance recommends that Congress increase HVRP funding to \$50 million.* HVRP, which is within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer outreach, job placement, and supportive services to homeless veterans. HVRP is the primary employment services program accessible by homeless veterans and is the only targeted employment program for any homeless subpopulation. It is estimated that this program only reaches about two percent of the overall homeless veteran population. An appropriation at the authorized level of \$50 million would enable HVRP grantees to reach approximately 19,866 homeless veterans.

### Goal #2 – Connecting Homeless Families, Individuals and Youth to Mainstream Services

#### **Social Services Block Grant (SSBG)**

*The Alliance recommends that Congress increase SSBG funding to \$2.3 billion.* SSBG funds are essential for programs dedicated to ending homelessness. In particular, youth housing programs and permanent supportive housing providers often receive state, county, and local funds which originate from the SSBG. As the U.S. Department of Housing and Urban Development has focused its funding on housing, programs that provide both housing and social services have struggled to fund the service component of their programs. This gap is often closed using federal programs such as SSBG.

#### **Community Services Block Grant (CSBG)**

*The Alliance recommends that Congress rejects cuts and fund CSBG at \$ 725 million.* Funding cuts for CSBG will destabilize the progress communities have made toward ending homelessness by not only ending services directly provided by CSBG funds but limiting a community's ability to access other federal dollars, such as those provided by the Department of Housing and Urban Development. Community Action Agencies (CAAs), which are the primary local recipients of CSBG funding, are directly involved in housing and homelessness services. In several communities, CAAs lead the Continuum of Care (CoC). CoCs coordinate local homeless service providers and the community's McKinney-Vento Homeless Assistance Grant application process with the Department of Housing and Urban Development.

In the fiscal year 2006 Community Services Block Grant Information Systems report published by the U.S. Department of Health and Human Services, CAAs reported expending approximately \$42 million on housing-related services. In addition, approximately \$50 million was spent nationwide on youth services, some of which related to housing. States reported that 180,000 clients served with CSBG funds were homeless<sup>2</sup>.

#### **Foster Youth Education and Training Vouchers**

*The Alliance recommends that Congress appropriate \$60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program.* The Education and Training Voucher Program offers funds to foster youth and former foster youth to enable them to attend colleges, universities, and vocational training institutions. Students may

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<sup>2</sup> U.S. Department of Health and Human Services, Administration of Children and Families. The Community Services Block Grant FY 2006 Statistical Report. Prepared by the National Association for State Community Services Programs.

receive up to \$5000 a year for college or vocational training education. The funds may be used for tuition, books, housing, or other qualified living expenses. Given the large number of people experiencing homelessness who have a foster care history, it is important to provide assistance such as these education and training vouchers to stabilize youth, prevent economic crisis, and prevent future homelessness.

**Community Mental Health Performance Partnership Block Grant**

*The Alliance recommends that Congress appropriate \$486.9 million for the Community Mental Health Performance Partnership Block Grant.* The Mental Health Block Grant provides flexible funding to states to provide mental health services. Ending homelessness requires federal, state and local partnerships. Additional mental health funds will give states the resources to improve their mental health system and serve all people with mental health disorders better, including homeless populations. For example, block grant funds can be used to pay for services linked to housing for homeless people, thereby meeting the match requirements for projects funded through Shelter Plus Care or the Supportive Housing Program.

**Substance Abuse Prevention and Treatment (SAPT) Block Grant**

*The Alliance recommends that Congress appropriate \$1.929 billion for the SAPT Block Grant.* The SAPT Block Grant is the primary source of federal funding for substance abuse treatment and prevention for many low-income individuals, including those experiencing homelessness. Studies have shown that half of all people experiencing homelessness have a diagnosable substance use disorder. States need more resources to implement proven treatment strategies and work with housing providers to keep homeless populations, especially chronically homeless populations, stably housed.

**Conclusion**

Homelessness is not inevitable. As communities implement plans to end homelessness, they are struggling to find funding for the services that homeless and formerly homeless clients need to maintain housing. The federal investments in mental health services, substance abuse treatment, employment training, youth housing, veterans' services, and case management discussed above will help communities create stable housing programs and change social systems which will end homelessness for millions of Americans.

Public Testimony for the Record by the  
**NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS**  
 Related to Appropriations by the  
**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,  
 HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**  
 Concerning the  
**COMMUNITY SERVICES BLOCK GRANT**  
 May 1, 2009

*Submitted by: Jovita A. Tolbert, Director of Program Services  
 National Association for State Community Services Programs  
 Phone: (202) 624-5835 | Email Address: jtolbert@nascsp.org*

The National Association for State Community Services Programs (NASCSP), the national association representing state administrators of the Department of Health and Human Services' Community Services Block Grant (CSBG) and state directors of the Department of Energy's Low-Income Weatherization Assistance Program, would like to thank Congress for its continued support of the CSBG and requests an appropriation of \$800 million for fiscal year 2010. We are requesting \$800 million in CSBG funding for FY 2010 to ensure the CSBG Network has adequate resources to sustain its expanded efforts to address the long-term needs of those families affected by the current economic recession and those transitioning from welfare to work. In addition, increased funding would enable the network to continue and strengthen its efforts to assist low-income workers in remaining at work through supportive services such as transportation and child care. The across the board cuts to the CSBG funding in past years have severely decreased the ability of the CSBG Network to provide and enhance essential services to low-income Americans. It is essential that the CSBG funding be increased for FY 2010.

#### **BACKGROUND**

The states believe the CSBG is a unique block grant that has successfully transferred decision-making to the local level. Federally funded with oversight at the state level, the CSBG has maintained a local network of nearly 1,100 agencies which operate in 99% of counties in the nation. This network serves nearly **16.2 million low-income individuals, members of more than 6.4 million low-income families**, CSBG eligible entities, largely local Community Action Agencies (CAAs), provide states with a stable and guaranteed network of designated entities which are mandated to change the conditions that perpetuate poverty for individuals, families, and communities. There is no other program in the U.S. mandated by federal statute to respond to poverty. To fulfill that mandate, CAAs provide services based on the characteristics of poverty in their communities. For one community, this might mean providing job placement and retention services; for another, developing affordable housing. In rural areas, it might mean providing access to health services or developing a rural transportation system.

Since its inception, the CSBG has shown how partnerships between states and local agencies benefit citizens in each state. We believe it should be viewed as a model of how the federal

government can best promote self-sufficiency for low-income persons in a flexible, decentralized, non-bureaucratic and accountable way.

Long before the creation of the Temporary Assistance for Needy Families (TANF) block grant, the CSBG set the standard for private-public partnerships that work to revitalize local communities and address the needs of low-income residents. Family oriented, while promoting economic development and individual self-sufficiency, the CSBG relies on an existing and experienced community-based service delivery system of CAAs and other non-profit organizations to produce results for its clients.

#### **WHAT DO LOCAL CSBG AGENCIES DO?**

Since CAAs operate in rural areas as well as in urban areas, it is difficult to describe a typical Community Action Agency. However, one thing that is common to all is the goal of self-sufficiency for all of their clients. Reaching this goal may mean providing day care for a struggling single mother as she completes her General Equivalency Diploma (GED) certificate, moves through a community college course and finally is on her own supporting her family without federal assistance. Many CAAs administer the Head Start Program which helps meet the educational needs of low-income families. It may mean assisting a recovering substance abuser as he seeks employment. Many of the Community Action Agencies' clients are persons who are experiencing a one-time emergency. Others have lives of chaos brought about by many overlapping forces - a divorce, sudden death of a wage earner, illness, lack of a high school education, closing of a local factory or the loss of family farms.

CAAs provide access to a variety of opportunities for their clients. Although they are not identical, most will provide some, if not all, of the services listed below:

- ◆ a variety of crisis and emergency safety net services
- ◆ employment and training programs
- ◆ transportation and child care for low-income workers
- ◆ individual development accounts
- ◆ micro business development help for low-income entrepreneurs
- ◆ local community and economic development projects
- ◆ housing, transitional housing, and weatherization services
- ◆ Head Start
- ◆ energy assistance programs
- ◆ nutrition programs
- ◆ family development programs
- ◆ senior services

CSBG is the core funding which holds together a local delivery system able to respond effectively and efficiently, without a lot of red tape, to the needs of individual low-income households as well as to broader community needs. In addition, CSBG funds many of these services directly. Without the CSBG, local agencies would not have the capacity to work in their communities developing local funding, private donations and volunteer services and running programs of far greater size and value than the actual CSBG dollars they receive.

CAAs manage a host of other federal, state and local programs which makes it possible to provide a one-stop location for persons whose problems are usually multi-faceted. Over half (52%) of the CAAs manage the Head Start program in their community. Using their unique position in the community, CAAs recruit additional volunteers, bring in local school district personnel, tap into faith-based organizations for additional help, coordinate child care and bring needed health care services to Head Start centers. In many states they also manage the Low Income Home Energy Assistance Program (LIHEAP), raising additional funds from utilities for this vital program. CAAs may also administer the Weatherization Assistance Program and are able to mobilize funds for additional work on residences not directly related to energy savings that, for example, may keep a low-income elderly couple in their home. CAAs also coordinate their programs with the Community Development Block Grant program to stretch federal dollars and provide a greater return for tax dollars invested. They also administer the Women, Infants and Children (WIC) nutrition program, as well as job training programs, substance abuse programs, transportation programs, domestic violence and homeless shelters, and food pantries.

**For every CSBG dollar they receive, CAAs leverage \$5.59 in non-federal resources** (state, local, and private) to coordinate efforts that improve the self-sufficiency of low-income persons and lead to the development of thriving communities.

#### **WHO DOES THE CSBG SERVE?**

National data compiled by NASCSP show that the CSBG serves a broad spectrum of low-income persons, particularly those who are not being reached by other programs and are not being served by welfare programs. Based on the most recently reported data, from FY 2007 CSBG serves:

- ◆ More than 3 million families with incomes at or below the poverty level; of these customer families, 1.4 million are severely poor as they have incomes at or below 50% of the poverty guideline.
- ◆ More than 1.3 million families headed by single mothers.
- ◆ More than 1.7 million “working poor” families relying on wages or unemployment benefits as income.
- ◆ More than 384,000 TANF participant families, 23% of all TANF families nationwide.
- ◆ About 4 million children.
- ◆ Almost 2.7 million people without health insurance.
- ◆ Over 1.7 million adults who had not completed high school.

#### **MAJOR CHARACTERISTICS OF THE CSBG NETWORK**

Due to the unique structure of the CSBG, the CSBG Network has earned a reputation for its:



EMERGENCY RESPONSE: CAAs are utilized by federal and state emergency personnel as a frontline resource to deal with emergency situations such as floods, hurricanes and economic downturns. They are also relied on by citizens in their community to deal with individual family hardships, such as house fires or other emergencies.

In fact, during and after Hurricanes Katrina and Rita, the state CSBG offices and local CAAs quickly mobilized to provide immediate and long-term assistance to over 355,000 evacuees. This immediate assistance included, but was not limited to, transportation, food, medical check-ups, housing, utility deposits, job placement, and clothing. State CSBG offices and CAAs across the country coordinated their relief efforts with other agencies providing disaster relief assistance such as FEMA, Red Cross, and other faith-based and community-based organizations.

State CSBG offices, through their local network of CAAs, continue to provide the long-term assistance evacuees will need as they re-establish themselves through self-sufficiency and family development programs. These programs offer comprehensive approaches to selecting and offering supportive services that promote, empower and nurture the individuals and families seeking economic self-sufficiency.

LEVERAGING CAPACITY: In FY 2006, every CSBG dollar leveraged \$18.73 from all other sources. Of those leveraged funds, \$5.47 came from non-federal resources (state, local, and private) to coordinate efforts that improve the self-sufficiency of low-income persons and lead to the development of thriving communities.

VOLUNTEER MOBILIZATION: CAAs mobilize volunteers in large numbers. In FY 2006, the most recent year for which data are available, the CAAs elicited more than 44 million hours of volunteer efforts, the equivalent of almost 21,187 full-time employees. Using just the minimum wage, these volunteer hours are valued at nearly \$227 million.

ADAPTABILITY: CAAs provide a flexible local presence that governors have mobilized to deal with emerging poverty issues.

Moreover, the CSBG Network has also earned a reputation for its:

ACCOUNTABILITY: The federal Office of Community Services, state CSBG offices, and CAAs have worked closely to develop a results-oriented management and accountability (ROMA) system. Through this system, individual agencies determine local priorities within six common national goals for CSBG and report on the outcomes that they achieved in their communities.

LOCAL DIRECTION AND OVERSIGHT: Tri-partite boards of directors guide CAAs. These boards consist of one-third elected officials, one-third representatives from the private sector, and not less than one-third of the members are representative of the low-income persons in the neighborhoods served by the CAA. The boards are responsible for establishing policy and approving business plans of the local agencies. Since these boards represent a cross-section of the local community, they guarantee that CAAs will be responsive to the needs of their community.

The statutory goal of the CSBG is to ameliorate the effects of poverty. The primary goal of every CAA is self-sufficiency for its clients. Helping families become self-sufficient is a long-term process that requires multiple resources. This is why the partnership of federal, state, local and private enterprise has been so vital to the successes of the CAAs.

#### EXAMPLES OF CSBG AT WORK

Since 1994, CSBG has implemented a Results-Oriented Management and Accountability (ROMA) system. Through ROMA, the effectiveness of programs is captured through the use of goals and outcomes measures. Below you will find several of the network's nationally aggregated outcomes achieved by individuals, families and communities as a result of their participation in innovative CSBG programs during FY 2007:

- ◆ Increased Economic Asset Enhancement and Utilization
  - **694,000** Low-income households achieved an increase in financial assets or financial skills as a result of Community Action assistance.
- ◆ Procured Supports to Reduce or Eliminate Barriers to Employment
  - **1.3 million** Low-income participants obtained supports which reduced or eliminated barriers to initial or continuous employment through assistance from Community Action.
- ◆ Gained Employment
  - **193,000** Low-income participants in Community Action employment initiatives got a job, obtained an increase in employment income, or achieved "living wage" employment and benefits.
- ◆ Improved Child and Family Development
  - **2.9 million** Infants, children, youth, parents, and other adults participated in developmental or enrichment programs facilitated by Community Action and achieved program goals.
- ◆ Secured Independent Living for Low-Income Vulnerable Populations
  - **2 million** Low-income vulnerable individuals received services from Community Action and maintained an independent living situation as a result.

At the end of the day, the CSBG Network represents our abiding national commitment to care for the less fortunate and in recognition that we are stronger when we do so. The CSBG and CSBG Network, in addition to other non-profit faith-based and community-based organizations, are a critical complement to the public sector's efforts towards helping to lift low-income Americans and their communities out of poverty and into self-sufficiency.

In fiscal year 2007, **the CSBG Network assisted approximately 20% of the persons in poverty that year and almost 15 million low-income individuals who are members of more than 6.4 million low-income families.** Renewed funding for the CSBG Network is one of the best ways to ensure that America has an experienced, guaranteed and trusted network to assist its working and vulnerable families in achieving and maintaining self-sufficiency. As such, **NASCSP requests \$800 million in CSBG funding for fiscal year 2010.**

## **ANAD**

### **NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS**

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#### **WRITTEN TESTIMONY**

**March 17, 2009**

**U.S. House of Representatives**

**Appropriations Committee**

**Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies**

Founded in 1976, the National Association of Anorexia Nervosa and Associated Disorders (ANAD) is our nation's first non-profit organization dedicated to education, early detection, and prevention of anorexia nervosa, bulimia nervosa, binge eating disorder, obesity, and related eating disorders.

Eating disorders are severe mental illnesses which often have significant physical health consequences for their victims, including malnutrition, obesity, and diabetes, as well as death due to cardiac arrest, organ failure, blood imbalances, and suicide. Anorexia nervosa has the highest mortality rate of any mental illness. An estimated six percent of those who have the disease die as a result. These disorders also frequently lead to or co-occur with other serious illnesses such as severe depression, alcoholism, and drug abuse.

Eating disorders are at epidemic levels in America. An estimated seven million women and one million men have eating disorders. These illnesses affect all segments of society—the young and old, the rich and poor, and all races and ethnicities, including African Americans, Asian Americans, Latino Americans, and Native Americans. But this is an epidemic that can be averted with education and prevention programs, and cured with early diagnosis and appropriate treatment.

Data from an ANAD survey of 18 middle and high schools in 15 states indicates that eating disorders are almost as prevalent as alcohol or drug problems among female

middle school and high school students. The survey also indicates that our schools are spending far less time on eating disorder prevention than on alcohol or drug prevention programs. Seventeen percent of the schools surveyed spent one hour per year on eating disorder education. Eleven percent of the schools surveyed had no eating disorder prevention program of any kind.

The failure to fund eating disorder education and prevention in schools is especially troubling in light of the fact that eating disorders are often accompanied by or lead to alcoholism or drug addiction, as well as diabetes, severe depression, and suicide.

Tens of millions of dollars are spent each year at the local, state, and federal levels to ensure that our children are properly educated to the dangers of alcohol and drugs. The value of such programs has been proven and accepted in schools throughout the country. With eating disorders almost as prevalent as alcohol and drug abuse in our schools, it is imperative that we provide more support for eating disorder prevention efforts in our middle schools and high schools. Millions of our youth can benefit from proven, low-cost educational and preventive measures that help faculty and students to understand and avoid the dangers of eating disorders.

Eating disorder research into the underlying causes and risk factors associated with eating disorders is just as important as education and prevention. As we continue to learn more about underlying causes, risk factors and predictors through medical research, it will undoubtedly improve the efficacy of our education and prevention efforts.

Based on the foregoing, ANAD respectfully makes this request of the Subcommittee with regard to funding priorities for Fiscal Year 2010. Millions of our youth can benefit from proven, low cost services that assist students to understand and avoid the dangers of eating disorders. Programs, such as those provided by ANAD's Eating Disorders and Obesity Education/Prevention Program for Middle and High Schools, promote the elements of a healthy lifestyle: self-acceptance, a good diet, adequate exercise and sufficient sleep.

Given the troubling lack of education and prevention in our schools, ANAD respectfully requests \$4 million or \$75.00 per school be allocated to place these life-enhancing programs in every middle and high school in the United States. This \$4 million in funds is above and beyond the current request in the Administration's proposed budget, for the Department of Education's Safe and Drug-Free Schools programs to provide grants for eating disorder prevention and education programs in our nation's middle schools and high schools.

Eating disorders cause serious physical problems that can last a lifetime. They rob people of their ability to function as productive members of society because, if not

properly treated, victims of these illnesses find themselves requiring more and more costly medical services throughout their lives. With early education and detection, eating disorders are treatable and at a much lower economic and personal cost to society.

Thank you for this opportunity to provide the Committee with this Written Testimony and corresponding appropriations request.

***For more information, please contact ANAD's Washington Representative, Tiffany Smith, at 202-263-3882 or [TSmith@mayerbrown.com](mailto:TSmith@mayerbrown.com), or ANAD Vice President, Christopher Athas, at 847-831-3763.***

### Summary of ANAD Eating Disorders Study

Data from a 2005 ANAD study shows that eating disorders are almost as prevalent as alcohol or drug problems in middle and high school female students. The study also shows that far less time is spent on eating disorder prevention than on alcohol or drug prevention programs.

This is especially significant since eating disorders are often accompanied by or lead to severe depression, suicidal tendencies, self mutilation or diabetes. Many victims become alcohol or drug addicted.

Eating disorders cause great suffering for victims and families and are expensive to treat. Anorexia nervosa has the highest mortality rate of any mental illness. An estimated six percent of all anorexics die from an eating disorder or from complications from their disorder. However, these very dangerous illnesses can be cured and prevented.

Eight middle schools and ten high schools from 15 states were surveyed for this study.

#### Incidence of Alcoholism, Drugs and Eating Disorders in Schools:

9.8% of girls have problems with alcohol

8% of girls have problems with drugs

7.8% of girls have problems with eating disorders

#### Time Devoted to Education/Prevention

Time devoted to Alcohol Education/Prevention.....12.3%

Time devoted to Drugs Education/Prevention.....13.8%

Time devoted to Eating Disorders  
Education/Prevention..... 6.2%

Three schools reported one hour per year was spent on eating disorders education and two schools reported that they did not have any program.

**Testimony on FY 2010 Federal Funding for Mental Health Services**

**Submitted to the House Appropriations Subcommittee on Labor, Health, and Human Services, Education, and Related Agencies**

**The Hon. Dave Obey (WI), Chairman**

**The Hon. Todd Tiahrt (KS), Ranking Member**

**Submitted by National Association of State Mental Health Program Directors (NASMHPD)**

**May 1, 2009**

Chairman Obey, Ranking Member Tiahrt, and members of the Subcommittee, on behalf of the National Association of State Mental Health Program Directors (NASMHPD), thank you for the opportunity to submit testimony on behalf of the \$29.5 billion public mental health service delivery systems serving 6.1 million people annually in all 50 states, four territories, and the District of Columbia. NASMHPD is the only national association to represent state mental health commissioners/directors and their agencies. In addition, NASMHPD has an affiliation with the approximately 220 state psychiatric hospitals. Our members administer and manage community-based systems of care for the millions of individuals with serious mental illness who at times require immediate access to a variety of inpatient facilities and psychiatric units in general hospitals but are often cared for successfully in the community.

A Substance Abuse and Mental Health Services Administration (SAMHSA)-funded October 2006 report by NASMHPD and the NASMHPD Research Institute, Inc. illustrates how dire the need is for people with mental illness. This report states that persons with serious mental illness die, on average, 25 years earlier than the general population. In addition, according to the SAMHSA, an estimated 17 million adults ages 18 and older (8.0 percent of the adult population) reported experiencing at least one major depressive episode during the past year. Finally, in the RAND Corporation's 2008 report, "Invisible Wounds of War: Psychological and Cognitive Injuries, Their Consequences, and Services to Assist Recovery," researchers concluded that there needs to be a nationwide effort to expand and improve the capacity of the mental health system to provide adequate care to members of the military and veterans. RAND further reported that this effort must involve the public mental health system, as well as the military and veteran health care systems.

**The Community Mental Health Services Block Grant (Block Grant):**

NASMHPD recommends providing an additional \$100 million for a total of \$520.7 million for the Block Grant. While this would be a significant increase over the current funding of \$420.7 million, the block grant program has lost nearly 50 percent of its purchasing power since 1983. An additional \$100 million in funding would help states meet the growing need for mental health services during a time of extreme strain on the public mental health safety net.

With the unemployment rate at a record high and the number of foreclosures rising, more individuals are seeking the services of the public mental health system. Just one example of the increase in need is that the National Suicide Prevention Lifeline, a 24-hour service sponsored by the Substance Abuse and Mental Health Services Administration, has experienced a 28.9% increase in the number of calls it has received over the past year. The loss of employment and housing often has a deleterious impact on the entire family resulting in an increased demand for mental health services.

Despite this growing need, many states are under significant budget pressure and are being forced to cut back on mental health programs. A recent study by NASMHPD and the NASMHPD Research Institute (NRI) reports that 32 state mental health agencies (SMHAs) are experiencing budget shortfalls for this year and FY 2010, and, in response, all are reducing services. Even in states that have not indicated a budget shortfall, there is evidence of financial stress in the mental health system. SMHAs have cut programs including, but not limited to, state inpatient hospitals, clinic services, day services, and targeted case management. Cuts at the state level reverberate, impacting counties and other localities, as well as nonprofit organizations that serve individuals with mental health needs.

Although mental health treatment relies significantly on Medicaid funding, many individuals needing mental health services are not eligible for their state's Medicaid program and use state-provided services, many of which are funded through the Block Grant. The Block Grant program has not received any additional significant federal funds in almost a decade. An increase of \$100 million to the Block Grant would greatly benefit the individuals who need services and have lost coverage due to the distressed economy.

The Block Grant is the principal federal discretionary program supporting community-based mental health services for adults and children. States use Block Grant funding to provide a range of critical services for adults with serious mental illnesses and children with serious emotional disturbances, including employment and housing assistance, case management, school-based support services, family and parenting education, and peer support.

The Block Grant is vital because it gives each state the flexibility to: fund services that are tailored to meet the unique needs and priorities of consumers of the public mental health system in that state; hold providers accountable for access to, and quality of services provided; and coordinate services to help finance medical and social services that individuals with mental illnesses need to live safely and effectively in the community.

#### **Programs of Regional and National Significance (PRNS)**

NASMHPD recommends providing \$398.5 million for PRNS, which represents a \$54 million increase over FY 2009.



The Center for Mental Health Services (CMHS) addresses priority mental health care needs of regional and national significance by developing and applying best practices, providing training and technical assistance, building targeted capacity expansion, and changing the service delivery system through family, client-oriented and consumer-run activities. Several important programs that will be positively affected by an increase in PRNS funding include, but are not limited to:

*Suicide Prevention for Children and Adolescents:*

In 2004, 32,439 individuals died by suicide in the U.S. Of these suicides, more than 4,500 were young people between the ages of 10-24. Nationally, suicide is the third leading cause of death among children aged 10-14 and among adolescents and young adults aged 15-24. According to the final report of President Bush's New Freedom Commission on Mental Health (2003), "our Nation's failure to prioritize mental health is a national tragedy...No loss is more devastating than suicide. Over 30,000 lives are lost annually to this largely preventable public health problem...Many have not had the care in the months before their death that would help them to affirm life. The families left behind live with shame and guilt..."

CMHS funds two specific suicide prevention initiatives. The first initiative is the National Suicide Prevention Lifeline (1-800-273-TALK), a network of more than 120 crisis centers across the country that respond, 24 hours a day, to individuals in emotional distress or suicidal crisis. In 2007, SAMHSA and the Department of Veterans' Affairs partnered to expand the reach of the Lifeline to provide for specialized veteran services. The second initiative is the Suicide Prevention Resource Center, which provides prevention support, training, and materials to strengthen suicide prevention efforts.

*Mental Health Transformation State Incentive Grants:*

The Mental Health Transformation State Incentive Grants (T-SIGs) support states' efforts to create comprehensive mental health plans and enhance the use of existing resources to serve persons with mental disorders. SAMHSA awarded seven T-SIGs in FY 2005; two additional T-SIGs were awarded in FY 2006. Grant funds can only be used for infrastructure changes, such as planning, collaborating, blended funding or developing service concepts, and policies and procedures that support a transformation agenda. Funding of direct mental health services must come from other sources. Grantees work closely with other agencies, such as criminal justice, housing, child welfare, Medicaid and education.

Federal funding for the State Incentive Grants supports states' efforts to develop more comprehensive state mental health plans. These plans facilitate the coordination of federal, state and local resources to support effective and dynamic state infrastructure to best serve persons with mental disorders.

*Alternatives to Seclusion and Restraint State Infrastructure Grants:*

Deaths due to seclusion and restraint in mental health and substance abuse care are estimated at approximately 150 per year across the United States. In addition to the risk

of death and injury, individuals who have experienced previous physical or sexual abuse can suffer further traumatization when subjected to these practices.

The Alternatives to Seclusion and Restraint State Infrastructure Grant Project (S/R-SIG) provides training, technical assistance and other support to States, providers, facilities, and consumers and families in order to reduce and eliminate seclusion and restraint practices. SAMHSA awarded eight S/R-SIGs in FY 2007. Most of these states are implementing best practices alternatives in multiple settings and with a variety of consumers.

*National Center for Trauma-Informed Care:*

The psychological effects of violence and trauma in our society are pervasive, highly disabling, yet largely ignored. Recent research indicates that interpersonal violence and trauma, including sexual and/or physical abuse, are widespread and have a major impact on a wide range of social problems which are costly if not addressed.

The National Center for Trauma-Informed Care provides technical assistance and training to publicly-funded agencies, programs, and services in order to encourage an environment that supports and empowers trauma survivors.

**Grants for Primary and Behavioral Health Care Integration**

NASMHPD supports a funding level of \$7.9 million for Grants for Primary and Behavioral Health Care Integration. This funding will assist community mental health centers address the co-occurring chronic illnesses that people with mental illnesses often experience. The 25-year shortened life span of people with mental illness makes investment in their overall health outcomes imperative.

**Projects for Assistance in Transition from Homelessness (PATH)**

NASMHPD recommends providing \$69.1 million for PATH, which represents a \$9.4 million increase over FY 2009.

The PATH formula grant program provides funding to states, localities and non-profit organizations to support individuals who are homeless (or are at risk of homelessness) and have a serious mental illness and/or a co-occurring substance abuse disorder. PATH is designed to encourage the development of local solutions to the problem of homelessness and mental illness through strategies such as aggressive community outreach, case management and housing assistance. Other important core services include referral for primary care, job training and education. Surveys indicate that, in 2005, 463 PATH-funded local agencies enrolled more than 82,000 individuals of diverse racial and ethnic background with the most disabling mental illness. The most common diagnoses were schizophrenia, psychotic disorders and affective disorders. More than half of homeless consumers at first contact had been homeless for more than 30 days.

**National Institute of Mental Health (NIMH)**

NASMHPD recommends providing \$1,552.0 million for NIMH, which represents a \$101.5 million increase over FY 2009.

The mission of NIMH is to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. Mental illnesses are fundamentally brain disorders that affect children, adolescents, and adults. Each year, more than 54 million people experience significant symptoms caused by mental disorders. This equates to one in every 20 adults who experience a disabling mental disorder. Of the ten leading causes of disability in the United States and internationally for individuals aged 15-44, four are mental disorders: major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. Left untreated, a mental disorder can lead to more severe and more difficult to treat illnesses, and to the development of co-occurring mental disorders.

NIMH is currently developing a Strategic Plan to: promote discovery in the brain and behavioral sciences to fuel research on the causes of mental disorders; determine when, where and how to intervene; develop new and better interventions that incorporate the diverse needs of people with mental disorders; and strengthen the public health impact of NIMH-supported research. NIMH must achieve the fundamental understanding of how mental disorders begin and progress, to discover new treatments, and eventually prevent and cure them.

#### **Other Important Funding Recommendations**

- Substance Abuse Prevention and Treatment Block Grant for \$1,928.6 million
- Center for Substance Abuse Prevention Programs of Regional and National Significance for \$276.0 million
- Center for Substance Abuse Treatment Programs of Regional and National Significance for \$489.3 million
- SAMHSA Integrated Treatment for Co-Occurring Serious Mental Illness and Substance Abuse Disorders for \$3.95 million
- National Institute on Alcohol Abuse and Alcoholism (NIAAA) for \$481.7 million
- National Institute on Drug Abuse (NIDA) for \$1,105.1 million

#### **Conclusion**

Thank you for your continued support for mental health initiatives. If you have any questions, please do not hesitate to contact Elizabeth Prewitt, NASMHPD's Director of Government Relations, 66 Canal Center Plaza, Suite 302, Alexandria, VA, Fax: 703-548-9517, Phone: 703-682-5196, [elizabeth.prewitt@nasmhpd.org](mailto:elizabeth.prewitt@nasmhpd.org).



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**Testimony of the National Coalition of STD Directors  
 Concerning the Public Health Budget for Fiscal Year 2010**

**Submitted for the Record to the House Appropriations Subcommittee on Labor,  
 Health and Human Services and Education  
 May 1, 2009**

The National Coalition of STD Directors is a nonprofit, nonpartisan association of public health sexually transmitted (STD) program directors in the 65 CDC directly funded project areas, which includes all 50 states, 7 cities and 8 U.S. territories. As the only national organization with a constituency that provides frontline STD services, NCSD is the leading national voice for strengthening STD prevention, research and treatment. These efforts include advocating for effective policies, strategies, and sufficient resources, as well as increasing awareness of the medical and social impact of STDs.

We appreciate this opportunity to provide the Subcommittee with information about the health crisis caused by the persistent and staggeringly high rates of STDs in the United States and about the programs of the Centers for Disease Control and Prevention (CDC) that combat these diseases.

The United States has the highest STD rates in the industrialized world, with more than 19 million people contracting an STD annually. In one year, our nation spends over \$8.4 billion to treat the symptoms and consequences of STDs. The indirect costs are higher, including lost wages and productivity, as well as human costs such as anxiety, shame, anger, depression and the challenges of living with infertility or cancer. The health consequences of STDs include: chronic pain, infertility, pregnancy complications, pelvic inflammatory disease, cervical cancer, birth defects and increased vulnerability to HIV, the virus that causes AIDS. Persons with a pre-existing STD have a 3 to 5 fold increased risk of acquiring HIV through sexual contact. In addition, studies have shown that HIV-infected persons who are also infected with other STDs are more likely to transmit HIV. Comprehensive STD treatment can reduce the likelihood of HIV transmission.

STDs have a disproportionate impact on young people, women, men who have sex with men (MSM) and racial and ethnic minorities. Of the approximately 19 million new STD infections each year, nearly half are among young people ages 15 to 24. Chlamydia, which leads to infertility, is the most frequently reported disease in the United States. Nearly 1 million women will have a severe case of pelvic inflammatory disease due to STDs. The transmission of STDs to babies -- prenatally, during birth or after -- can cause serious life-long complications including physical disabilities, developmental disabilities and death. Men who have sex with men (MSM) have historically experienced high rates of all STDs, including HIV/AIDS. In 2007, 65% of all primary and secondary syphilis cases were among MSM. The syphilis rate among males is now six times the rate among females, a dramatic disparity that did not exist a decade ago, when rates were nearly equivalent between the sexes. This trend suggests that the increase in cases among men have been primarily among men who have sex with men. Persons of color, particularly African-Americans, American Indians/Alaskan Natives, and Hispanics are also at higher risk of contracting STDs. In 2007, the rate of Chlamydia among African Americans was 8 times that of whites, for American Indian/Alaskan Natives it was 5 times higher than whites, and for Hispanics it was 3 times higher than whites. African American women experience syphilis rates 14 times higher than white women. Socioeconomic, cultural and linguistic barriers to quality healthcare and STD prevention and treatment services have likely contributed to a higher prevalence and incidence of STDs among racial and ethnic minorities.

While rates of STDs in this country have continued to skyrocket, federal funding for CDC's Division of STD Prevention has steadily declined since Fiscal Year 2003. For every dollar spent on STD prevention, \$43 is spent each year on STD-related costs. In addition, for every dollar spent on research, \$92 is spent each year on STD related costs.

**The National Coalition of STD Directors requests an FY 2010 funding level of \$451.3 million, an increase of \$299 million, for the STD prevention, treatment and surveillance programs of the Centers for Disease Control and Prevention.** These funds will significantly enhance the CDC's ability to reduce STD rates across the country.

#### Public Health Infrastructure (+\$40 million)

Federal funding for CDC's Division of STD Prevention has been relatively flat for the past 15 years. The combined effect of this, along with steadily increasing rates of STDs and more recently, drastic state and local budget cuts due to the economic crisis, STD programs are in crisis mode and stretched thinner than ever. STD programs have had to cut staff, dramatically cut clinical services or close clinic doors altogether, and eliminate critical services such as free condom distribution programs. The public health infrastructure must be rebuilt and modernized. Investments in training, information and surveillance systems, public health laboratories, and better diagnostic technologies would increase efficiency, ensure program effectiveness and protect the health of future generations.

Public Health Workforce (+\$24 million)

A critical piece of rebuilding the public health infrastructure is scaling up the public health workforce. One quarter of the current public health workforce will be eligible to retire by 2012. We must invest now in training and retraining the next generation of public health professionals. This is particularly critical for STD programs. The underpinning of all STD programs is the Disease Intervention Specialist (DIS), who provide partner services to individuals infected with STDs, their partners, and to other persons who are at increased risk for STD infection. DIS are specially trained public health workers who are responsible for locating, counseling and coordinating the testing of individuals exposed to an STD. DIS complete an intensive CDC training course, which provides a strong foundation in field investigation techniques, both on the ground and on the internet. In some states, DIS also assist in the HIV Partner Services (PS) program, by assisting newly HIV-infected individuals with informing their partners of their status and encouraging those partners to seek HIV counseling, testing and related prevention services. DIS also provide surge capacity during an emergency response, such as the current swine flu epidemic. The versatile expertise of DIS make them indispensable during a public health crisis, and also highlights the need for increased resources to support the training and hiring of new DIS. The current economic crisis has forced many states to freeze the hiring of new DIS and even lay off DIS, in spite of increasing STD cases.

Expand Chlamydia Screening and Infertility Prevention (+\$100 million)

Chlamydia is the most commonly reported disease in the United States, as well as the primary cause of infertility. The *Infertility Prevention Project* (IPP), a collaborative effort between CDC and Office of Population Affairs within HHS, has been working to reduce STD related infertility for 15 years. IPP provides funding to screen low-income women for chlamydia and gonorrhea in STD and family planning clinics. This project is a major success story in STD prevention, having been highly successful in reducing new cases of chlamydia and gonorrhea in areas where it has been implemented. However, additional resources are needed to bring this project to scale and reach a greater number of at-risk women. Chlamydia screening has also been shown to be extremely cost effective. Among 21 evidence-based clinical services recommended by the U.S. Preventive Service Task Force (USPSTF), chlamydia screening for young women ranked among the top 5 as having the most health benefits and best value for the dollar.

Additional federal resources would help support increased chlamydia screening in the public sector, expand school-based and correctional-based screening, as well as initiate a series of demonstration projects in the private sector aimed at increasing private sector screening rates.

Gonorrhea Control and Health Disparities Reduction (+\$78 million)

Gonorrhea is the second most commonly reported infectious disease in the U.S. African Americans are the most heavily impacted by this disease, with overall rates 19 times greater than that of whites in 2007. African American men aged 15 to 19 years old experience gonorrhea rates 39 times higher than white men in the same age group. An increasing issue of concern in the treatment of gonorrhea is antimicrobial drug resistance. In 2006, 13.8% of all gonorrhea cases

demonstrated resistance, while 39% of the cases specifically among MSM demonstrated resistance. In 2007, CDC revised its gonorrhea treatment guidelines to include only a single class of antibiotics.

Additional federal resources would be used to monitor antimicrobial resistant gonorrhea and test alternate or new drug regimens, initiate culturally competent social marketing campaigns, increase screening and partner services in hyperendemic areas, and develop demonstration research projects to determine the effectiveness and cost-effectiveness of gonorrhea prevention and control interventions.

#### Syphilis Elimination (+\$50 million)

The rates of primary and secondary syphilis, the most infectious stages of the disease, decreased throughout the 1990s, and in 2000 reached an all-time low. However, since 2000 as STD funding has declined, the syphilis rate in the U.S. has increased by 76%. Since 1999, the *Syphilis Elimination Effort* (SEE), a collaboration between CDC and state, local, and non-governmental partners, has worked to eliminate syphilis from all areas of the country and reduce long-standing health disparities. These strategies include: expanded surveillance and outbreak response activities, rapid screening and treatment in and out of medical settings, expanded laboratory services, strengthened community involvement and agency partnerships, and enhanced health promotion. These efforts have been shown to be successful, but must be funded adequately. A 2008 study suggested that SEE funding in a given year was associated with subsequent declines (over the following two years) in syphilis rates in a given state. The greater a state's per capita syphilis elimination funding in a given year, the greater the decline in syphilis rates in subsequent years. While the activities of SEE have proven themselves to be effective, they must be adequately and consistently funded to ultimately eliminate this disease in the United States.

Additional federal resources for SEE would be prioritized for increased screening, particularly among HIV positive persons and pregnant women, the development and evaluation of rapid diagnostic tests, implementation of social marketing campaigns targeted towards men who have sex with men (MSM) and minority populations, and expanded screening in correctional facilities.

#### Build a Response to Viral STDs (Herpes, HPV, Hepatitis B)

Over 45 million Americans, almost 26% of the U.S. population, are infected with herpes simplex virus (HSV), a treatable but incurable viral STD. Improved treatment of HSV is fundamental to reducing the rates of transmission. Individuals with herpes are more susceptible to acquiring HIV. An estimated 20 million Americans are infected with human papillomavirus (HPV), the cause of about 90% of all cervical cancer cases. CDC would utilize additional funds to monitor the HPV vaccine introduction and behavioral impact of HPV vaccine through demonstration projects and an expansion of an existing, multi-level, multi-year behavioral research project. The most common source of hepatitis B virus (HBV) infection among adults is sexual contact. Funding is needed to expand prevention efforts on HPV and HBV and to deliver education on the availability of preventive vaccines.

**The National Coalition of STD Directors also requests an FY 2010 funding level of \$0 for the Community-Based Abstinence Education (CBAE) program, within the Administration for Children and Families (ACF).**

Federal investment in abstinence-only-until-marriage programs have shown no effectiveness at delaying sexual activity, reducing rates of STDs, including HIV and/or unintended pregnancy. In order to reduce the staggering rates of STDs among young people, sexuality education programs must be medically sound and effective in fostering healthy behavior over the long-term. While abstinence is an important component of comprehensive sexuality education and the only 100% effective method of preventing STDs, when advocated as the sole option, research has shown that it is ineffective, unrealistic, and potentially harmful for young people. NCSD believes the federal government should only support sexuality education programs that are evidence-based. For that reason, we support the elimination of all funding for the Community-Based Abstinence Education (CBAE) program. All such funds should be re-directed to evidence-based prevention and education programs.

We urge the Committee to substantially increase resources to protect our nation from the devastating consequences of STDs. The CDC has developed programs that have significantly reduced STD rates and the associated costs to society. We know how to prevent, control and treat sexually transmitted diseases; however, without additional funds, the CDC cannot implement these programs to scale in all 50 states, U.S. territories and directly funded cities.



## NATIONAL CONGRESS OF AMERICAN INDIANS

NATIONAL CONGRESS OF AMERICAN INDIANS TESTIMONY ON  
FISCAL YEAR 2010 BUDGET

*House Committee on Appropriations, Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
April 9, 2009*

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On behalf of the tribal nations of the National Congress of American Indians (NCAI), we are pleased to present our recommendations for FY 2010 funding of Indian programs in the Departments of Labor, Health and Human Services, and Education. President Obama released a broad budget plan for FY 2010 and from what NCAI has reviewed of the blueprint so far, the new Administration plans to ensure America's promise extends to the entire nation, including throughout Indian Country.

After tribes witnessed years of declining resources for critical Indian programs in the federal budget, the attention the Administration's FY 2010 proposed budget has given to tribal priorities is a welcome change. The chairman of this subcommittee has heard often of the social and economic challenges facing Indian Country. This subcommittee has also heard that the recent resurgence of tribal self-determination has resulted in measurable improvements in the poverty, income, and unemployment among Indian people.

Indian tribes are re-building our nations in ways that honor our ancestors and cultures as well as meeting the demands and opportunities of living in the modern world. An analysis of socio-economic change between 1990 and 2000 showed that Indian Country economies grew at a faster pace than the economy as a whole. Although Indian tribes have made great strides in addressing the long accumulated economic deficits in our communities, much work remains to be done. Tribes also have a critical role to play in the recovery as the nation pulls out of the current destructive recession. As the President and Congress aim to invest in people to strengthen the middle class and the drivers of economic growth, NCAI looks forward to tribal self-determination playing a part in the solution. To ensure tribes continue to make progress, sustained investment in tribal governments and programs that support self-determination will be critical in FY 2010. With the new Administration and the FY 2010 budget request, there is renewed hope in Indian Country.

The President's FY 2010 budget priorities appear to align with many of Indian Country's priorities: education, health care, infrastructure, and clean energy. Below are some budget recommendations for the Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

Tragically, over the last year, nearly 3,000 American Indians and Alaska Natives died of cardiovascular disease, over 16,500 were diagnosed with a sexually transmitted disease, 5,000 were diagnosed with diabetes for the first time, over 22,000 are now living with cancer (45 percent of which were diagnosed in the late-stages), and 400 took their own life. These people are our tribal leaders; our daughters and sons; our mothers and fathers; and, our brothers and sisters. For over 100 years, Native people have experienced inferior health outcomes. Our life expectancy is still five years less than that of other Americans. Adequate funding is needed to end this lasting injustice and uphold the federal trust responsibility of the United States and the Federal government.

- **Provide \$1 billion overall for Head Start funding.**
- **Provide \$10 million for Esther Martinez language programs under the Administration for Native Americans.**
- **\$15 million to fund SAMHSA Behavioral Health Services Grants for American Indian and Alaska Natives.**
- **Increase Circles of Care, SAMHSA by \$5 million**

#### *ADMINISTRATION FOR CHILDREN AND FAMILIES*

Head Start: Over the past 40 years, Head Start has played a major role in the education of Indian children and in the well-being of many tribal communities. However, because of inadequate funding, only about 16 percent of the age-eligible Indian child population is enrolled in Indian Head Start. The comprehensive nature of this program integrates education, health, and family services. Since it closely mirrors a traditional Indian educational model, it is one of the most successful federal programs operating in Indian Country. Despite these successes, Head Start funding has declined by 14 percent over the last six years, after factoring in inflation. Head Start should be funded at a rate substantially greater than inflation to make up for prior year cuts and also to trigger special Indian expansion funds that Congress provided when the Head Start Act was reauthorized in 2007.

- **\$1 billion –Head Start Funding (overall)**

#### *ADMINISTRATION FOR NATIVE AMERICANS*

Native Languages: Throughout Indian Country, tribes are combating the loss of traditional languages by advocating for and instituting language programs within their communities. These language programs serve Native communities by preventing the loss of tribal traditions and cultures. The tribal students in these language immersion programs perform substantially better academically, including on national tests, than Native students who have been enrolled in such programs.

- **\$10 million - Esther Martinez language programs under the Administration for Native Americans**

*SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)*

American Indian and Alaska Native Grant Program: This grant program within the Substance Abuse and Mental Health Service Administration has been authorized to award grants to Indian health programs to provide the following services: prevention or treatment of drug use or alcohol abuse, mental health promotion or treatment services for mental illness. To date, these funds have never been appropriated.

- **\$15 million to fund SAMHSA Behavioral Health Services Grants for American Indian and Alaska Natives.**

Circles of Care: Increase funding to \$10 million a year for the Circles of Care children's mental health grant program under Programs of National and Regional Significance under the Substance Abuse and Mental Health Services Administration. This grant program has historically been funded at about \$5 million a year, which provides for approximately seven tribal grants during each three-year grant cycle. The program has been very successful and has spawned several new tribal children's mental health programs in Indian Country that as a result have been self sustaining.

- **Increase of \$5 million**

**DEPARTMENT OF EDUCATION**

The Administration intends to make investments in education so all Americans can have the chance to receive a world class education from cradle to career. The 2007 National Indian Education Study indicated that in reading and math, American Indian and Alaska Native students scored significantly lower than their peers in both fourth and eighth grades. To ensure that Native students—from pre-school to college—meet the same challenging academic standards as other populations and experience the benefits of a quality and supportive education, it is imperative that the federal government uphold its responsibility for the education of Indian people.

- **Provide \$195.5 million for Title VII funding under the No Child Left Behind Act.**
- **Increase Impact Aid funding 10% to adjust for inflation and population growth (\$1,365 million).**
- **Provide \$32 million for Title III, Higher Education Act.**
- **Provide \$62 million (one-time) forward funding for Tribal Colleges and Universities.**
- **Provide \$10 million for Tribal Education Departments.**

Title VII Funding: This funding provides critical support for culturally based education approaches for American Indian and Alaska Native students and addresses the unique educational and cultural needs of Native students. It is well-documented that Native students are more likely to thrive in environments that support their cultural identities while introducing different ideas. Title VII has produced many success stories within our communities, but increased funding is critical in this area to bridge the achievement gap for Native students.

- **\$195.5 million**

Impact Aid Funding: Impact Aid provides resources to public schools whose tax bases are reduced because of federal activities, including the presence of an Indian Reservation. Impact Aid affects Native children living on or near tribal lands and children of military families living on or near bases. Approximately 95 percent of American Indian and Alaska Native youth are educated in public schools. Impact Aid funding must be adjusted based on population increases and inflation.

- **Increase Impact Aid Funding 10% to Adjust for Inflation and Population Growth (\$1,365 million)**

Tribal Colleges and Universities: Titles III and V of the Higher Education Act, known as Aid for Institutional Development programs, support institutions with a large proportion of financially disadvantaged students and low cost-per-student expenditures. Tribal Colleges and Universities (TCUs) fit this definition. The nation's 36 TCUs serve some of the most impoverished areas in the nation, yet they are the country's most poorly funded postsecondary institutions. Congress recognized the TCUs as young and struggling institutions and authorized a separate section of Title III (Part A, Sec. 316) specifically to address their needs. Additionally, a separate section (Sec. 317) was created to address similar needs of Alaska Native and Native Hawaiian institutions. Section 316 is divided into two competitive grants programs: Formula funded basic development grants and competitive single year facilities construction grants. Under the Tribal College Act, securing the one-time payment to transition institutional operating grants to a forward funded program would finally end the cycle of delayed payments, short-term loans, and lay-offs that currently plague Tribal Colleges and Universities each year; and, further for the first time, it would provide these institutions the resources they need at the start of each academic year.

- **\$32 million - Title III, Higher Education Act**
- **\$62 million (one-time) forward funding for Tribal Colleges and Universities**

Tribal Education Departments: Over 100 Indian tribes have started Tribal Education Departments (TED). TEDs develop and administer policies, gather and report data and perform critical research to help tribal students from early childhood through higher and adult education. TEDs serve thousands of tribal students nationwide in BIA, tribal and public schools. They also cultivate leadership skills and train a potential workforce. Funding for TEDs has been authorized by Congress but never appropriated in either the BIA budget or that of the U.S. Department of Education. Both of these authorizations are retained in the No Child Left Behind Act of 2001. Tribes must have access to funding in order to close the achievement gaps so that tribal students will be better equipped to perform well in school. We recommend that \$5 million of the funding be directed from the Department of Interior and \$5 million of the funding be directed from the Department of Education.

- **\$10 million - Tribal Education Departments**

**CONCLUSION**

NCAI realizes Congress must make difficult budget choices this year. As elected officials, tribal leaders certainly understand the competing priorities that you must weigh over the coming months. However, the federal government's constitutional and treaty responsibility to address the serious needs facing Indian Country are unique. These responsibilities remain unchanged, whatever the economic climate and competing priorities may be. We at NCAI urge you to make a strong, across-the-board commitment to meeting the federal trust obligation by fully funding those programs that are vital to the creation of vibrant Indian Nations. Such a commitment, coupled with continued efforts to strengthen tribal governments and to clarify the government-to-government relationship, truly will make a difference in helping us to create stable, diversified, and healthy economies in Indian Country.

**Testimony of the National Consumer Law Center, on Behalf of Our Low-Income Clients  
Before the House Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies**

**FY 2010 Appropriations for the Low Income Home Energy Assistance Program**

Prepared by Olivia Wein, Staff Attorney, National Consumer Law Center  
(202-452-6252, owein@nclcdc.org)

The federal Low Income Home Energy Assistance Program (LIHEAP)<sup>1</sup> is the cornerstone of government efforts to help needy seniors and families avoid hypothermia in the winter and heat stress (even death) in the summer. LIHEAP is an important safety net program for low-income, unemployed and underemployed families struggling in this economy. In FY 2009, the program is expected to assist 7.3 million low-income households afford their energy bills. Residential consumers continue to pay much higher heating bills than in the past, and depending on the region of the country and the heating fuel, the increase in expenditures for heating fuel have been substantial over time. *In light of the crucial safety net function of this program in protecting the health and well-being of low-income seniors, the disabled and families with very young children, we respectfully request that LIHEAP be fully funded at its authorized level of \$5.1 billion for FY 2010 and that advance funding of \$5.1 billion be provided for the program in FY 2011.*

**Home Energy Bills Remain High at a Time When Unemployment and Underemployment is Growing**

Residential heating expenditures remain at high levels. Average residential heating expenditures this winter are expected to be about 38% higher for heating oil, 16% higher for natural gas, 42% higher for propane, and 24% higher for electricity when compared to the five-year average for 2002-2007.<sup>2</sup> The steady, high energy bills are hitting low-income households struggling in this economic downturn. According to the Bureau of Labor Statistics, in March 2009, the number of unemployed workers was 13.2 million, with half the increase in the number of unemployed occurring within the past four months.<sup>3</sup> According the Economic Policy Institute, the number of involuntary part-time workers nearly doubled to over 8 million in the past year, largely due to full-time workers accepting reduced hours.<sup>4</sup> The hardship low-income households face is also apparent in the data below on the number of households falling behind.

**States' Data On Electric and Natural Gas Disconnections and Arrearages Show That More Households Are Falling Behind**

The steady and dramatic rise in residential energy costs has resulted in increases in electric and natural gas arrearages and disconnections. For example, in **Rhode Island** in 2008 there were 8% more service disconnections for non-payment than in any other year on record, and 21% of those

<sup>1</sup> 42 U.S.C. §§ 8621 et seq.

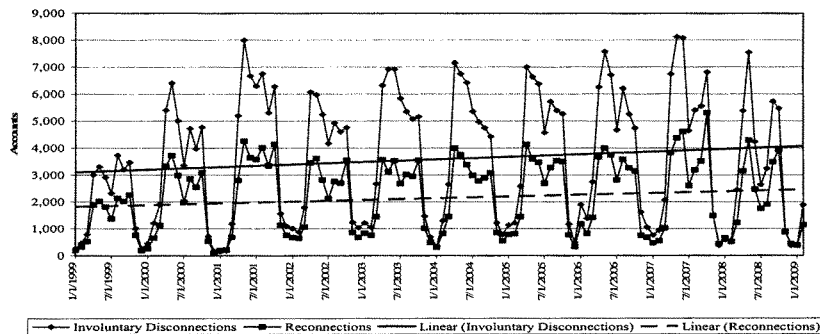
<sup>2</sup> Derived from data in the Energy Information Agency, Short-Term Energy Outlook (Feb. 2009), Table WF01.

<sup>3</sup> US, DOL, Bureau of Labor Statistics, *The Employment Situation: March 2009* (rel. April 3, 2009).

<sup>4</sup> See Ross Eisenbrey and Kathryn Edwards, *Downtime: Workers forced to settle for fewer hours*, Economic Policy Institute (Jan. 14, 2009).

accounts were not restored.<sup>5</sup> A recent national survey by the National Association of Regulatory Utility Commissioners found that almost 40 million electricity and natural gas residential consumers held nearly \$8.7 billion in past due accounts at the end of the 2007-2008 Winter heating season. The survey also concluded that in calendar year 2007, 8.7 million residential consumers had their electricity or natural gas service terminated for failing to pay their bills, with 3.6 million who remained disconnected as of this past May 2008.<sup>6</sup> The chart below of data from **Iowa**<sup>7</sup> is illustrative of the seasonal cycle of disconnections and restorations. It shows the alarming gap between service disconnections and reconnections has been increasing over time, suggesting increased durations of service loss and greater numbers of households that do not regain access to service under their own accounts.

**Iowa Electric and Natural Gas Utilities:  
Residential Service Disconnections and Reconnections**



Although there are winter utility shut-off moratoria in place in many states, not every home is protected against energy shut-offs in the middle of winter. As we approach the lifting of winter shut-off moratoria, we expect to see a wave of disconnections as households are unable to afford the cost of the energy bills. Low-income families are falling further behind as we endure year after year of rising home energy prices. We expect the disconnection peaks to grow and the gap between disconnections and reconnections to also grow, especially in light of the economic challenges faced by the unemployed and underemployed workers.

**Iowa:** Iowa has experienced a steady increase in enrollment for the regular LIHEAP program from FY 2007 to FY 2009 with 86,000 households in 2007; 87,000 in 2008 and projects 95,700 in FY 2009.<sup>8</sup> As a testament to the difference LIHEAP can make for low-income households, in February 2009, the number of Iowa low-income households with past due energy accounts and the total amount of the low-income arrears were lower than for the past three years at this

<sup>5</sup> Analysis of John Howat, senior policy analyst at National Consumer Law Center (April 2009).

<sup>6</sup> Sandra Sloane, Mitchell Miller, Beverly Barker, Lisa Colosimo, "2008 Individual State Report by NARUC Consumer Affairs Subcommittee on Collections Data Gathering." (Approved on Nov. 17, 2008 by the NARUC Consumers Affairs Committee).

<sup>7</sup> Chart provided by the Iowa Bureau of Energy Assistance.

<sup>8</sup> NEADA press releases from April 25, 2008 and January 12, 2009.

point in time (e.g., February 2006, February 2007 and February 2008). Comparatively, when looking at the arrearage data for February over time for the total residential gas and electric accounts in arrears and the amount of those arrears, those numbers are at historic highs.<sup>9</sup>

**Ohio:** Ohio has experienced a steady and dramatic demand for low-income energy assistance. The number of households entering into the state's low-income energy affordability program, the Percentage of Income Payment Program (PIPP), increased 9% from January 2008 to January 2009. The increase is an even more dramatic 86% between January 2003 and January 2009. The total dollar amount owed (arrearage) by low-income PIPP customers increased 11% from January 2008 to January 2009 and 52% when comparing PIPP customer arrears from January 2003 to January 2009.<sup>10</sup> Ohio has experienced a steady increase in enrollment for the regular LIHEAP program (HEAP) from FY 2007 to FY 2009 with 360,000 households in 2007; 370,000 in 2008 and projects 400,000 in FY 2009.<sup>11</sup>

**Pennsylvania:** Pennsylvania has also experienced a steady increase in enrollment for the regular LIHEAP program from FY 2007 to FY 2009 with 367,000 households in 2007; 398,000 in 2008 and projects 490,000 in FY 2009.<sup>12</sup> Utilities in Pennsylvania that are regulated by the Pennsylvania Public Utility Commission (PA PUC) have established universal service programs that assist utility customers in paying bills and reducing energy usage. Even with these programs, electric and natural gas utility customers find it difficult to keep pace with their energy burdens. The PA PUC estimates that more than 17,745 households entered the current heating season without heat-related utility service -- this number includes about 3,373 households who are heating with potentially unsafe heating sources such as kerosene or electric space heaters and kitchen ovens. In mid-December 2008, an additional 13,595 residences where electric service was previously terminated were vacant and over 6,442 residences where natural gas service was terminated were vacant. In 2008, the number of terminations increased 73% compared with terminations in 2004. As of December 2008, 18.3% of residential electric customers and 16.9% of natural gas customers were overdue on their energy bills. These 2008 overdue utility bills have increased 9.57 % over 2007. In addition, in recognition of the increases in media reports of deaths of terminated customers the PA PUC implemented a new reporting requirement. Utilities in Pennsylvania are now required to file reports regarding any incidents involving death at locations where residential utility service has been terminated.<sup>13</sup> The economic downturn is putting additional pressures on local human service agencies as well. A report on the effect of economy on Pittsburgh, Pennsylvania shows a 73.3 % increase in "first time" applicants for a range of basic needs assistance, including energy assistance.<sup>14</sup>

**States are Predicting Record LIHEAP Participation:** NEADA reports that for FY 2009, 15 states have projected increases in participation of at least 21%, with Texas estimating a 201% increase, Florida 200%, California 162%, Tennessee 60%, Arkansas 50%, Arizona 35%, Alaska 34%, New Mexico 26%, Oregon 26%, Alabama 25%, Massachusetts 25%, New

<sup>9</sup> Based on data provided by the Iowa Bureau of Energy Assistance.

<sup>10</sup> Public Utilities Commission of Ohio.

<sup>11</sup> NEADA press releases from April 25, 2008 and January 12, 2009.

<sup>12</sup> NEADA press releases from April 25, 2008 and January 12, 2009.

<sup>13</sup> Pennsylvania Public Utility Commission Bureau of Consumer Services.

<sup>14</sup> Vivien Luk and Stacy Kehoe, *Understanding the Impact of the Economic Downturn on Pittsburgh Residents and Human Service Agencies*, the Forbes Funds (November 2008).



**Hampshire 25%, Pennsylvania 23%, Connecticut 23% and Delaware 21%.<sup>15</sup>** In Arkansas, many of the community action agencies are estimating that about 40% of the people contacting them for services over the past eight to ten months are new applicants; overwhelmingly, these new applicants are seeking utility assistance.<sup>16</sup> Thus there is great need for a fully funded LIHEAP program in the states.

**LIHEAP Is a Critical Safety Net Program for the Elderly, the Disabled and Households With Young Children**

LIHEAP Is Vital To Poor Seniors: Poor seniors are cutting back on energy usage because it is not affordable. In general, elder households use less total household energy than non-elderly households, which is attributable primarily to the smaller dwelling units. However, poor elderly households use markedly less energy than non-poor elderly households. Even worse, poor elderly households, on average, consume 12% more energy per square foot of living space (this measurement is also referred to as energy intensity) than non-poor elderly households. This disparity is attributable to the poorly weatherized living spaces and the use of old, inefficient heating equipment and appliances.<sup>17</sup> LIHEAP is critical for helping low-income seniors maintain safe temperatures in their homes.

Dire Choices and Dire Consequences: Recent national studies have documented the dire choices low-income households face when energy bills are unaffordable. Because adequate heating and cooling are tied to the habitability of the home, low-income families will go to great lengths to pay their energy bills. Low-income households faced with unaffordable energy bills cut back on necessities such as food, medicine and medical care.<sup>18</sup> The U.S. Department of Agriculture has released a study that shows the connection between low-income households, especially those with elderly persons, experiencing very low food security and heating and cooling seasons when energy bills are high.<sup>19</sup> A pediatric study in Boston documented an increase in the number of extremely low weight children, age 6 to 24 months, in the three months following the coldest months, when compared to the rest of the year.<sup>20</sup> Clearly, families are going without food during the winter to pay their heating bills, and their children fail to thrive and grow. The loss of essential utility services can be devastating, especially for poor families that can find themselves

<sup>15</sup> NEADA press release, *Applications for Low Income Energy Assistance Reach Record Levels: States Call on Congress to Increase Funding for LIHEAP* (January 12, 2009).

<sup>16</sup> Estimates provided by Arkansas Community Action Agencies Association, Inc.

<sup>17</sup> NCLC analysis of U.S. Energy Information Administration, 2001 Residential Energy Consumption Survey data on elderly energy consumption and expenditures.

<sup>18</sup> See e.g., National Energy Assistance Directors' Association, *2008 National Energy Assistance Survey*, Tables in section IV, G and H (April 2009) (To pay their energy bills 32% of LIHEAP recipients went without food, 42% went without medical or dental care, 38% did not fill or took less than the full dose of a prescribed medicine, 15% got a payday loan). Available at <http://www.neada.org/communications/press/2009-04-28.htm>.

<sup>19</sup> Mark Nord and Linda S. Kantor, *Seasonal Variation in Food Insecurity Is Associated with Heating and Cooling Costs Among Low-Income Elderly Americans*, *The Journal of Nutrition*, 136 (Nov. 2006) 2939-2944.

<sup>20</sup> Deborah A. Frank, MD et al., *Heat or Eat: The Low Income Home Energy Assistance Program and Nutritional and Health Risks Among Children Less Than 3 years of Age*, *AAP Pediatrics* v.118, no.5 (Nov. 2006) e1293-e1302. See also, Child Health Impact Working Group, *Unhealthy Consequences: Energy Costs and Child Health: A Child Health Impact Assessment Of Energy Costs And The Low Income Home Energy Assistance Program* (Boston: Nov. 2006) and the *Testimony of Dr. Frank Before the Senate Committee on Health, Education, Labor and Pensions Subcommittee on Children and Families* (March 5, 2008).

facing eviction. A 2007 Colorado study found that the second leading cause of homelessness for families with children is the inability to pay for home energy.<sup>21</sup>

When people are unable to afford paying their home energy bills, dangerous and even fatal results occur. In the winter, families resort to using unsafe heating sources, such as space heaters, ovens and burners, all of which are fire hazards. In 2006, 73% of home heating fire deaths, 43% of home heating fire injuries and 51% of property damage from home heating fires involved stationary or portable space heaters.<sup>22</sup> In the summer, the inability to keep the home cool can be lethal, especially to seniors. According to the CDC, older adults, young children and person with chronic medical conditions are particularly susceptible to heat-related illness and are at a high risk of heat-related death. The CDC reports that 3,442 deaths resulted from exposure to extreme heat during 1999-2003.<sup>23</sup> The CDC also notes that air-conditioning is the number one protective factor against heat-related illness and death.<sup>24</sup> LIHEAP assistance helps these vulnerable seniors, young children and medically vulnerable persons keep their homes at safe temperatures during the winter and summer and also funds low-income weatherization work to make homes more energy efficient.

LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable low-income seniors, the disabled and families with young children. **LIHEAP must be fully funded at its authorized level of \$5.1 billion in FY 2010 in light of the steady increase in home energy costs and the increased need for assistance to protect the health and safety of low-income families by making their energy bills more affordable during this economic downturn. In addition, FY 2011 advance funding would facilitate the efficient administration of the state LIHEAP programs.** Advanced funding provided certainty of funding levels to states to set income guidelines and benefit levels before the start of the heating season. States can also plan the components of their program year (e.g., amounts set aside for heating, cooling and emergency assistance, weatherization, self-sufficiency and leveraging activities).

<sup>21</sup> Colorado Interagency Council on Homelessness, *Colorado Statewide Homeless Count Summer, 2006*, research conducted by University of Colorado at Denver and Health Sciences Center (Feb. 2007).

<sup>22</sup> John R. Hall, Jr., *Home Fires Involving Heating Equipment: Space Heaters* (In 2006 there were an estimated 64,100 home fires involving space heaters resulting in 540 deaths, 1,400 injuries and \$943 million in property damage) National Fire Protection Association (Jan. 2009).

<sup>23</sup> CDC, "Heat-Related Deaths – United States, 1999-2003" MMWR Weekly, July 28, 2006.

<sup>24</sup> CDC, "Extreme Heat: A Prevention Guide to Promote Your Personal Health and Safety" available at [http://emergency.cdc.gov/disasters/extremeheat/heat\\_guide.asp](http://emergency.cdc.gov/disasters/extremeheat/heat_guide.asp).

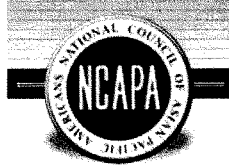
Testimony of

Floyd Mori

Chair, National Council of Asian Pacific Americans (NCAPA)

Before the Subcommittee on Labor, Health & Human Services, Education and Related  
Agencies

House of Representatives Committee on Appropriations



Thank you, Chairmen Obey, Ranking Member Tiahrt, and Members of the Subcommittee for the opportunity to submit testimony before the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. We submit this testimony on behalf of National Council of Asian Pacific Americans (NCAPA) on the education concerns and needs of our communities.

Founded in 1996, the National Council of Asian Pacific Americans (NCAPA) is a coalition of twenty-six organizations that advocate for the interests of Asian Americans, Native Hawaiians, and other Pacific Islanders on the national level. It is united by a vision that empowers and engages Asian American and Pacific Islander (AAPI) community members into the political and electoral processes. NCAPA advocates on behalf of issues impacting almost 14 million AAPIs living in the United States from more than 48 different ethnic groups and speaking more than 100 different languages. We wish to highlight the educational needs of the AAPI community in regards to the Asian American and Native American Pacific Islander Serving Institutions (AANAPISI) bill.

Congress took an important step in passing the AANAPISI bill in 2007 by rejecting the “model minority” myth, which inaccurately categorizes the complex AAPI population as a homogenous, academically successful unit that is not in need of any support systems. According to the July 2007 GAO report on AAPIs in higher education, “...viewing Asian American and Pacific Islanders as a homogenous group may mask differences in educational attainment and income among Asian American and Pacific Islander subgroups.” In reality, a large number within the AAPI community fall well below national averages with respect to both income and education due to unique historical or socio-economic factors including refugee status, long-term disenfranchisement, and poverty. For example, according to the 2000 Census, of people aged 25 and older, 24.2 percent of Samoan-, 38.1 percent of Vietnamese-, 49.6 percent of Laotian-, 53.3 percent of Cambodian-, and 59.6 percent of Hmong Americans have less than a high school graduate level of education – as compared to 19.6 percent of the national population. Additionally, compared to 12 percent of the total U.S. population, more than 29 percent of Cambodian- and 37 percent of Hmong Americans live below the federal poverty line.

Similar to other minority serving institution programs, the AANAPISI program seeks to increase the capacity of higher education institutions to better serve all disadvantaged college students, not singling out AAPIs. Eligible colleges can use the AANAPISI grants for a variety of services, including curriculum development, classroom renovation, partnership development with community-based organizations, outreach to students of all levels, and research and data collection for AAPI populations and subpopulations.

Six universities received almost \$10 million in grants of this historic program due to their exceptional five-year plans that address the specific needs of the AAPI population. The schools that received the funding this past year were:

City College of San Francisco (CA)  
 Foothill-De Anza Community College (AZ)  
 Guam Community College (GU)  
 Seattle Community College (WA)  
 University of Hawaii at Hilo (HI)  
 University of Maryland – College Park (MD)

Individual plans differ between the six awarded institutions from constructing a new resource center for AAPI students; to recruiting more AAPI students into science, engineering, technology and mathematics (STEM) fields; to strengthening an Asian American Studies Program; to developing more work-study opportunities that will support the retention of AAPI students, particularly those with financial needs. All six applications include outreach to their respective surrounding AAPI communities to encourage youth to pursue postsecondary education.

As Larry Shinagawa, Director of the Asian American Studies Program at the University of Maryland – College Park and one of the AANAPISI grantees, notes:

“We have been able to develop a long-term and sustainable approach to expanding Asian American and Pacific Islander activities at the University of Maryland and the adjoining regions. The fundamental purpose of increasing recruitment, retention, and graduation of this important population has been done through expanding courses, programming and professionalizing and expanding our outreach and communications with academic institutions, student organizations, non-profit agencies and government entities. The grant expands experiential study opportunities both abroad and nationally and also research to cover all ethnicities that make up the diaspora.”

We strongly believe that investing in education at all levels is absolutely necessary to ensure the success of all students, including AAPIs. In particular, **we urge you to fully fund the Asian American and Native American Pacific Islander Serving Institutions (AANAPISI) program at \$30 million for fiscal year 2010** to support underserved college students including whole portions of AAPIs in overcoming substantial barriers to finishing college.

Thank you for the opportunity to present NCAPA's views on appropriations to the Subcommittee today. We look forward to working with you to ensure a vibrant federally-funded Asian American and Native American Pacific Islander Serving Institutions (AANAPISI) program.



Written Testimony Submitted by:  
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Submitted May 1, 2009 to the United States House Committee  
on Appropriations Subcommittee on Labor, Health &  
Human Services, Education, and Related Agencies  
The Honorable David Obey, Chairman

Mr. Chairman and Members of the Subcommittee:

As Chairperson of the National Down Syndrome Society, I want to take this opportunity to thank you for the leadership role this Subcommittee has played over the years in supporting and creating awareness on Down syndrome. I am pleased to offer the following written testimony regarding appropriation requests for Down syndrome in Fiscal Year (FY) 2010.

There are more than 400,000 people living with Down syndrome in the U.S., and about 5,000 babies, or one in 800, that are born each year. Down syndrome occurs in people of all races and economic levels, and it is the most frequently occurring chromosomal condition. The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.

Advancements in the treatment of health problems have allowed people with Down syndrome to enjoy fuller and more active lives, and become more integrated into the economic and social structures of our communities. Unfortunately, while progress has also been made in public policies that enhance the lives of individuals with Down syndrome, barriers still exist, making it difficult for people to access adequate health care, housing, employment and education.

We have been working with Congress for decades to address these challenges and advance public policies that promote the acceptance and inclusion of individuals with Down syndrome, and help them to achieve their full potential in all aspects of their lives.

Mr. Chairman, we understand the challenges the Subcommittee faces in prioritizing requests, we believe that funding the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007 (Public Law 110-374) is imperative given the significant impact Down

syndrome has on families and communities across the country and the great potential for improvements in quality of life. On behalf of the National Down Syndrome Society, we recommend that you appropriate *\$5 million in the FY 2010 to implement the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007.*

As you know, last year, Congress passed the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007. This new law seeks to ensure that pregnant women receiving a positive prenatal diagnosis of Down syndrome and parents receiving a postnatal diagnosis will receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. It offers referrals to support services such as hotlines, websites, informational clearinghouses, adoption registries, parent support networks and Down syndrome and other prenatally diagnosed conditions programs. The goal is to create a sensitive and coherent process for delivering information about the diagnosis across the variety of medical professions and technicians, to avoid any conflicting, inaccurate or incomplete information. Also, the legislation would promote the rapid establishments of links to community supports and services for parents who choose to take their baby with Down syndrome home or for those who choose to have their child adopted.

It is estimated that more than 1,000 prenatal tests are available or in development. Included among them are tests for conditions that are not life-threatening, could be helped by surgery or medical care, or don't appear until adulthood. The prognoses for people with some prenatally diagnosable disabilities have been improving markedly in recent years, leaving medical professionals scrambling to keep up with changing data. By including \$5 million in the FY 2010 Labor, Health & Human Services, Education, and Related Agencies Appropriations Bill, the Department of Health and Human Services (HHS) will be able to fund its responsibilities to:

- Collect and distribute information relating to Down syndrome and other prenatally or postnatally diagnosed conditions;
- Coordinate the provision of supportive services for patients receiving a positive diagnosis of a prenatally or postnatally diagnosed condition; and
- Oversee the new requirements for health care providers established by the law. The funding is also needed to carry out the requirement that the CDC assist state and local health departments to integrate testing results into surveillance systems.

Mr. Chairman, thank you for your time and attention. Given the considerable impact this condition has on families and communities across the country, the promise of further assistance and improving research outcomes for individuals with Down syndrome is crucial. We are thrilled beyond measure that Congress enacted this legislation and hope that funding this request will help to shift the way the nation regards individuals with disabilities. Through providing accurate, updated information about diagnosable conditions like Down syndrome to pregnant women, the expectation is that individuals and families will make better, more informed decisions. But the bigger impact will be better understanding on the part of the American people about the nature of disability and the value of these citizens to their families, their communities and to our country. Should you have any questions or require additional information, please feel free to call on me.

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**TESTIMONY**  
**OF**  
**THE NATIONAL ENERGY ASSISTANCE DIRECTORS' ASSOCIATION**  
**BEFORE THE SUBCOMMITTEE ON**  
**LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,**  
**AND RELATED AGENCIES**  
**COMMITTEE ON APPROPRIATIONS**  
**U.S. HOUSE OF REPRESENTATIVES**  
**FY 2010 APPROPRIATIONS REQUEST FOR**  
**THE LOW INCOME HOME ENERGY ASSISTANCE PROGRAM**

**May 5, 2009**

**National Energy Assistance Directors' Association**  
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The members of the National Energy Assistance Directors' Association (NEADA) would like to first take this opportunity to thank the members of the Subcommittee for its continued program support. For FY 2010, funding was increased from \$2.57 billion to \$5.1 billion, the fully authorized funding level for the program. As a result, states were able to increase benefit levels and the number of households served to the highest level on record. Additional program funding has made a significant difference in the lives of millions of the nation's poorest families, especially for the newly unemployed and those who are suffering from reduced work hours as a result of the continuing recession.

For FY 2010 we are requesting the Subcommittee maintain full funding for LIHEAP in order to maintain services for the 7.2 million households expected to receive assistance in FY 2009 and provide \$600 million in emergency funding authority. In addition, we are also concerned that states will be hampered in their ability to administer their programs efficiently due to the lack of advanced funding. The lack of a final program appropriation prior to the beginning of the fiscal year creates significant administrative problems for states in setting their program eligibility guidelines. In order to address this concern, we are requesting advance appropriations of \$5.1 billion for FY 2011 and \$600 million in emergency contingency fund authority.

The President's 2010 Budget for LIHEAP would reduce funding to \$3.2 billion, assuming all emergency funds were released. At this lower level of funding, states would have little choice but to reduce the number of households served by more than 1.5 million and reduce the average grant by about \$70.

The Administration's proposal for an automatic adjustment or "trigger" in the event of rising prices for home energy offers the promise of providing additional stability for protecting the purchasing power of energy assistance appropriations. We do not believe that the provision provides an adequate substitute for fully funding LIHEAP. Rather we believe that this type of provision, including an adjustment for extreme weather conditions should be considered as a complement to a fully funded program at \$5.1 billion.

#### **The Impact of the FY 2009 Appropriation**

The increase in funding provided by the FY 2009 appropriation allowed states to increase the number of households served by 25 percent from 5.8 million to 7.3 million households, a record number. It also allowed states to increase the average benefit from \$332 to \$489, enough to cover about 50 percent of the cost of home heating. We are currently preparing to conduct the 2009 Home Energy Survey and the additional funding is expected to show improved outcomes, including reduced shut-off and arrearage rates for those receiving energy assistance.

Additional funding provided by the FY 2010 appropriation allowed states to reach out to the newly unemployed as well those continuing to struggle with higher energy bills. Twelve states reported increases of at least 25 percent, including two that increased by 200 percent: Texas 201 percent, Florida 200 percent, Tennessee 60 percent, Arkansas 50 percent, Vermont

27 percent, New Mexico 26 percent, and 25 percent for Alabama, California, Massachusetts, New Hampshire and Oregon.

Reports from the field clearly indicate that this is not the time to cut LIHEAP. Massachusetts, for example, reported that new applications for assistance are up by 55 percent from last year. The State of Wisconsin has reported that they are receiving calls from their local agencies that fuel oil and propane vendors will not deliver without arrears being paid in full even though the customer is receiving an energy assistance benefit.

Florida has reported major layoffs in industries supporting high ages of low-income workers - agriculture, building, and tourism – and that the agencies serving these families are being overwhelmed with record numbers of requests for assistance and applicants with shut-off notices and arrearages. Local LIHEAP providers are describing the need for additional assistance as "staggering" and "desperate."

#### **Energy Prices Remain High**

The recent decline in home heating oil and natural gas prices has helped to slow the rate of increase in home energy prices. However, prices remain high and for many low income Americans – unaffordable. As shown in the following table, average home heating costs have increased by 24 percent from \$793 during the winter of 2004-05 to \$990 during the recently completed winter heating season of 2008-09.

Winter Heating Season	Heating Oil	Natural Gas	Propane	Electricity	All Fuels
2004-05	\$1,176	\$738	\$1,103	\$722	\$793
2005-06	\$1,409	\$943	\$1,277	\$787	\$948
2006-07	\$1,445	\$815	\$1,347	\$828	\$900
2007-08	\$1,953	\$858	\$1,681	\$861	\$990
2008-09	\$1,622	\$866	\$1,642	\$925	\$986
% Change 2005-09	37.9 %	17.3%	48.9%	28.1%	24.3%
% Change 2008-09	-16.9%	0.9%	-2.3%	7.4%	2.0%

Source: Energy Information Administration, Short Term Energy Outlook, March 2009

#### **National Energy Assistance Survey**

Low income families struggle to pay their home energy bills and LIHEAP is the one way that many manage to do so. We recently completed the 2008 National Energy Assistance Survey (NEA). This survey documented changes in the affordability of energy bills, the need for LIHEAP, and the choices that low-income households make when faced with unaffordable energy bills. The survey confirmed many of the families receiving LIHEAP assistance are struggling to pay their home energy bills and that without LIHEAP many more would be facing shut-off of home energy service. Among the findings of the survey:

- Record numbers of households reported sacrificing to pay their home energy bills. As compared to 2003 survey, 32 percent vs. 22 percent went without food for at least a day; 42 percent vs. 38 percent went without medical or dental care and 38 percent vs. 30 percent did not fill prescription or took less than the full dose of medicine.
- Households reported that they took actions to reduce their energy bill that could be dangerous to their health or living situation: 44 percent closed off part of their home; 28 percent kept their home at a temperature that was unsafe or unhealthy; 23 percent left their home for part of the day and 33 percent used their kitchen stove or oven to provide heat.
- Many were shut-off from power because they were unable to pay their energy bills: 47 percent skipped paying or paid less than their entire home energy bill; 37 percent received a notice or threat to disconnect or discontinue their electricity or home heating fuel; 12 percent had their electric or natural gas service shut off in the past year due to nonpayment; 28 percent were unable to use their main source of heat in the past year because their fuel was shut off, they could not pay for fuel delivery, or their heating system was broken and they could not afford to fix it; 17 percent were unable to use their air conditioner in the past year because their electricity was shut off.
- High energy bills contributed to the high mortgage foreclosure rate: 28 percent did not make their full mortgage or rent payment; 4 percent were evicted from their home or apartment; 4 percent had a foreclosure on their mortgage; 11 percent moved in with friends or family and 3 percent moved into a shelter or were homeless.
- Payday lenders played provided loans to many families to pay their energy bills: 15 percent received a payday loan. Of particular concern, 26 percent of those with children under 18 reported taking out a payday loan as compared to 8 percent for seniors.
- Many of the LIHEAP recipients faced significant medical and health problems in the past five years, partly as a result of high energy costs. 32 percent went without food for at least one day; 42 percent went without medical or dental care; 38 percent did not fill a prescription or took less than the full dose of a prescribed medication; and 24 percent had someone in the home become sick because the home was too cold.

The members of NEADA recognize the difficult budget decisions that you face as you consider the funding levels for LIHEAP for FY 2010 and advance funding for FY 2011. We appreciate your interest and continued support for LIHEAP. Please feel free to call upon us if we can provide you with additional information.

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**National Federation of Community Broadcasters Testimony to the  
House Appropriations Subcommittee on Labor, Health and Human Services, Education  
and Related Agencies  
Regarding the Fiscal Year 2012 Appropriations  
for the Corporation for Public Broadcasting  
Encompassed in the Fiscal Year 2010 Appropriation Legislation**

**Testimony of Carol Pierson  
President and CEO  
510-451-8200 or [carol@nfcbs.org](mailto:carol@nfcbs.org)  
April 27, 2009**

Thank you for the opportunity to submit testimony to this Subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the President and CEO of the National Federation of Community Broadcasters (NFCB), I speak on behalf of 250 community radio stations and related individuals and organizations across the country. Nearly half our members are rural stations and half are controlled by people of color. In addition, our members include many Low Power FM stations that are putting new local voices on the airwaves. NFCB is the sole national organization representing this group of stations which provide independent, local service in the smallest communities of this country as well as the largest metropolitan areas.

In summary, the points we wish to make to this Subcommittee are that NFCB:

- Requests \$542 million in funding for CPB for FY 2012;
- **Supports a \$307 million supplemental appropriation in FY 2010 to ensure that public broadcasting is not lost to any parts of the country because of the economic crisis;**
- Requests \$40 million in FY 2010 for conversion of public radio and television to digital broadcasting;
- Requests \$27 million in FY 2010 for replacement of the radio interconnection system;
- Requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fundraising by public broadcasters;
- Supports CPB activities in facilitating programming and services to Native American, African American and Latino radio stations;
- Supports CPB's efforts to help public radio stations utilize new distribution technologies and requests that the Subcommittee ensure that these technologies are available to all public radio services and not just the ones with the greatest resources.

**Community Radio fully supports the appropriation of \$542 million in federal funding for the Corporation for Public Broadcasting in Fiscal Year 2012.** Federal support distributed through CPB is an essential resource for rural stations and for those serving communities of color. These stations provide critical, life-saving information to their listeners and are often in communities with very small populations and limited economic bases, thus the community is unable to financially support the station without federal funds. For example, these stations offer programming in languages other than English or Spanish, they can offer emergency information targeted for a particular geographic area, and can offer in-depth programming on public health issues.

In larger towns and cities, sustaining grants from CPB enable Community Radio stations to provide a reliable source of noncommercial programming about the communities themselves. Local programming is an increasingly rare commodity in a nation that is dominated by national program services and concentrated ownership of the media. Federal funding allows an alternative to exist in these larger markets. And with large newspaper shedding journalists, local community radio may be one of the only outlets able to pick up the slack in coverage of local political matters.

For over 30 years, CPB appropriations have been enacted two years in advance. This insulation has allowed public broadcasting to grow into a respected, independent, national resource that leverages its federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the federal funds. Most important, the insulation that advance funding provides “go[es] a long way toward eliminating both the risk of and the appearance of undue interference with and control of public broadcasting.” (*House Report 94-245.*)

For the past few years, CPB has increased support to rural stations and committed resources to help public radio take advantage of new technologies such as the internet, satellite radio and digital broadcasting. We support these new technologies we can better serve the American people, but want to ensure that smaller stations with more limited resources are not left behind in this technological transition. We ask that the Subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system, particularly rural and minority stations, utilize new technology.

NFCB commends CPB for the leadership it has shown in supporting and fostering programming services to Latino stations and Native American stations. For example, *Satélite Radio Bilingüe* provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues of particular interest to the Latino population in Spanish and English. At the same time, *Native Voice One (NV1)* is distributing politically and culturally relevant programming to Native American stations. There are now over 33 stations in the U.S. controlled by and serving Native Americans.

Five years ago, CPB funded the establishment of the Center for Native American Public Radio (CNAPR). After four years in operation, CNAPR has assisted with the renewal of licenses and expansion of the interconnection system to all Native stations and has advanced the opportunity for Native Nations to own their own, locally controlled station. In the process of this work, it was recognized that radio would not be available to all Native Nations and broadband and other new technologies would be necessary. CNAPR has been repositioned as Native Public

Media (NPM) and is working hard to double the number of Native stations within the next three years. These stations are critical in serving local, isolated communities (all but one are on Indian Reservations) and in preserving cultures that are in danger of being lost. CPB's 2003 assessment recognized that "...Native Radio faces enormous challenges and operates in very difficult environments." CPB funding is critical to these rural, minority stations. The funding of the Intertribal Native Radio Summit by CPB in 2001 helped to gather these isolated stations together into a system of stations that can support one another. The CPB assessment goes on to say "Nevertheless, the Native Radio system is relatively new, fragile and still needs help building its capacity at this time in its development." NPM promises to leverage additional new funding to ensure that these stations continue providing essential services to their communities.

CPB also funded a Summit for Latino Public Radio which took place in September 2002 in Rohnert Park, California, home of the first Latino public radio station. This year, CPB has provided funding to the Latino Public Radio Consortium to develop a Strategic Plan and Business Model to expand the service of public radio to the Latino population. The Latino population is growing in this country and requires news services geared toward them in order to fully participate in civic life. Hispanics were 12.5 percent of the population in 2000, by 2007 they were 15 percent, and the number is only growing.<sup>1</sup>

CPB plays an extremely important role in the public and Community Radio system: They convene discussions on critical issues facing us as a system. They support research so that we have a better understanding of how we are serving listeners. And, they provide funding for programming, new ventures, expansion to new audiences, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with media consolidation and new distribution technologies.

**Community Radio supports a \$307 million supplemental appropriation in FY 2010 to ensure that public broadcasting is not lost to any parts of the country because of the economic crisis.** Public Broadcasting is requesting a one-time investment of federal resources to help stations maintain local service and assist their communities cope with the economic crisis and to assure continuity of public broadcasting service to the American people. Financial contributions from corporations, foundations, institutions are down dramatically and listeners contributions, the main source of funding for Community Radio are beginning to be impacted by the growing unemployment. Community stations are critical sources of local information and it is essential that they be able to continue to provide their unique local service.

**Community Radio supports \$40 million in FY 2010 for the conversion to digital broadcasting by public radio and television.** While public television's digital conversion needs are mandated by the FCC, public radio is converting to digital to provide more public service and to keep up with commercial radio. The Federal Communications Commission has approved a standard for digital radio transmission that will allow multicasting. CPB has provided funding for more than 650 radio transmitters to convert to digital. Of those, 160 are multicasting two or more streams of programming. The development of second and third audio channels will potentially double or triple the service that public radio can provide listeners, particularly in un-served and underserved communities. However, this initial funding still leaves nearly 200 radio transmitters that must ultimately convert to digital or become obsolete.

<sup>1</sup> Pew Hispanic Center, Statistical Portrait of Hispanics in the United States, 2007.

**Community Radio strongly supports \$27 million in FY 2009 for the public radio interconnection system.** Public radio pioneered the use of satellite technology to distribute programming. The Public Radio Satellite System's recently-launched ContentDepot continues this tradition of cutting edge technology. Satellite capacity supporting it must be renewed and upgrades are necessary at the station and network operations levels. Interconnection is vital to the delivery of the high-quality programming that public broadcasting provides to the American people. This is the last year of a three-year request for \$80 million to the complete the project.

We are in a period of tremendous change. "Radio is well on its way to becoming something altogether new — a medium called audio."<sup>2</sup> The digital movement is transforming the way we do things; new distribution avenues like digital satellite broadcasting and the internet are changing how we define our business; and, the concentration of ownership in commercial radio makes public radio in general, and Community Radio in particular, more important as a local voice than we have ever been. New Low Power FM stations are providing local voices in their communities an avenue of expression, and many new community stations will be going on the air within the next few years. Community Radio is providing essential local emergency information, programming about the local impact of major global events taking place, and culturally-relevant information and entertainment in native languages, as well as helping to preserve cultures that are in danger of dying out. During the natural disasters of recent years, radio proved once again that it is the most dependable and available medium for getting emergency information to the public.

During these challenging times, the role of CPB as a convener of the system becomes even more important. The funding that it provides will allow smaller stations to participate alongside larger stations that have more resources as we move into a new era of communications.

Thank you for your consideration of our testimony. If the Subcommittee has any questions or wishes to follow up on any of the points expressed above, please contact:

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The **NFCB** is a 33-year-old grassroots organization which was established by, and continues to be supported by, our member stations. Large and small, rural and urban, NFCB member stations are distinguished by their commitment to local programming, community participation and community support. NFCB's 250 members come from across the United States, from Alaska to Florida, from every major market to the smallest Native American reservation. While urban member stations provide alternative programming to communities that include New York, Los Angeles, San Francisco, Chicago, and other major markets, rural members are often the sole source of local and national daily news and information in their communities. NFCB's membership reflects the true diversity of the American population: 41% of members serve rural communities, and 46% are radio services controlled by people of color.

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<sup>2</sup> The State of the News Media, Pew Project for Excellence in Journalism, 2008.

On Community Radio stations' airwaves examples of localism abound: on KWSO in Warm Springs, Oregon, you will hear morning drive programs in the Native language of that community; throughout the California farming areas in the central valley, Radio Bilingüe programs six stations targeting low-income farm workers; in Chevak, Alaska, on KCUK you will hear the local weather reports and public service announcements in Cup'ik/Yup'ik Eskimo; in Dunmore, West Virginia, you will hear coverage of the local school board and county commission meetings; KABR in Alamo, New Mexico serves its small isolated Native American population with programming almost exclusively in Navajo; and on WWOZ you can hear the sounds and culture of New Orleans throughout the day and night.





Written Testimony Submitted by:  
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Submitted May 1, 2009 to the United States House Committee  
 on Appropriations Subcommittee on Labor, Health &  
 Human Services, Education, and Related Agencies  
 The Honorable David Obey, Chairman

Mr. Chairman and Members of the Subcommittee:

As President of the Board of Directors for the National Fragile X Foundation, I want to take this opportunity to thank you for the leadership role this Subcommittee has played over the years in the fight for Fragile X-associated Disorders. I am pleased to offer the following written testimony regarding appropriation requests in FY 2010.

Fragile X-associated Disorders are genetic disorders that cause behavioral, developmental, and language disabilities across a person's lifespan. It is linked to a mutation on the X chromosome, and is the most common inherited form of intellectual disabilities. Fragile X is also linked to reproductive problems in women including early menopause (FXPOI) and, a Parkinson's-like condition in older male carriers (FXTAS). Over 100,000 Americans have Fragile X Syndrome and over one-million Americans carry a Fragile X mutation and either have, or are at risk for developing a Fragile X-associated disorder.

These appropriations requests are significant in order to continue to build the infrastructure needed and assure continued progress toward targeted treatments for Fragile X-associated Disorders. The National Fragile X Foundation has invested significantly in the creation of the Fragile X Clinical & Research Consortium, a network of 20 clinics across the country who collaborate to align data collection efforts, participate in clinical trials of new pharmacological agents, share research findings and develop consistent best practices and standards of care for the treatment of Fragile X-associated Disorders.

In addition, these appropriations requests would assist in building upon important work already initiated by the federal government. We have been successful at building programs at the Centers for Disease Control & Prevention (CDC), National Institutes of Health (NIH), and Health Resources and Services Administration (HRSA). The CDC has recognized the value of this important collaboration, and has provided resources to ensure the continued growth and evolution

of the Fragile X Clinical & Research Consortium. Previously, the CDC has secured nearly \$4.5 million in funding since FY 2005 for the CDC Fragile X National Public Health Initiative. The program is currently funded at just over \$1.8 million annually. Furthermore, the CDC has worked with Congress to define the highest impact public health priorities for the Fragile X community. These efforts led to:

- o Development of a newborn screening test for fragile X syndrome;
- o Single gene resource network for fragile X syndrome;
- o Fragile X syndrome cascade testing and genetic counseling protocols;
- o Fragile X Family Needs Assessment; and
- o Support for the Fragile X Clinical & Research Consortium.

Moreover, public efforts, including three National Institute of Child Health and Human Development (NICHD)-funded Fragile X Research Centers, has proven critically important in the development of effective treatments. The development of key therapeutics for Fragile X will likely be effective for a much larger population living with related autism spectrum disorders. We recognize that in order to translate basic science findings into viable treatments for Fragile X, additional coordination and resources are required at the NIH.

The Fragile X community has been working to promote the work of NIH to ensure improved coordination among the various institutes to ensure the most effective use of federal research dollars devoted to Fragile X-associated Disorders (i.e., Fragile X Syndrome, Fragile X-associated Tremor/Ataxia Syndrome, and Fragile X-associated Primary Ovarian Insufficiency). Congress has advocated for greater resources at NIH leading to an increase in NIH Fragile X-associated Disorders efforts from approximately \$12 million annually in 2001 to approximately \$27 million in FY 2009. With this increase, NIH recently awarded the largest Fragile X federal research grant in history, a 5-year, \$21.8 million grant to a team of researchers at the UC Davis School of Medicine and M.I.N.D. Institute.

As you know, the FY 2008 Departments of Labor, Health & Human Services, Education and Related Agencies Appropriations Act included language directing the NIH, under the leadership of the NICHD (Senate Report 110-107) to coordinate, intensify, and expedite research efforts related to Fragile X-associated Disorders. The law specifically directed the NIH to convene a scientific session in 2008 to develop pathways to new opportunities for collaborative, directed research across institutes, and to produce a blueprint of coordinated research strategies and public-private partnership opportunities for Fragile X. The NICHD was directed to lead this initiative and was urged to collaborate with the three existing federally-funded Centers of Excellence as well as the Fragile X Clinical & Research Consortium.

In response to this directive, NICHD leadership convened a two-day scientific session and created a rigorous working group infrastructure consisting of the world's leading researchers and NIH staff to ensure timely development of the NIH Research Blueprint on Fragile-X associated disorders. The leadership team at NICHD and three working groups prepared a comprehensive blueprint that will provide a clear direction for future research activities for Fragile-X associated disorders. The final draft of this report was completed in late 2008, and will be published by NIH this week.

Mr. Chairman, we respectfully request Congress to continue its support of these ongoing initiatives, and to support increased prioritization of Fragile X-associated Disorders at the CDC and NIH in order to accelerate the critical work being accomplished through the Fragile X Clinical & Research Consortium.

**The National Fragile X Foundation recommends that you appropriate the following FY 2010 requests:**

- (1) A **\$2 million increase** in funding from FY 2009 levels, for the National Fragile X Public Health Initiative and other **Centers for Disease Control and Prevention (CDC)** initiatives to:
  - Focus efforts on identifying ongoing needs, effective treatments and positive outcomes for families by increasing epidemiological research, surveillance, screening efforts, and the introduction of early interventions and supports for individuals living with Fragile X-associated Disorders.
  - Focus on the continued growth and development of initiatives that support health promotion activities and foster rapid, high-impact translational research practice for the successful treatment Fragile X-associated Disorders, including ongoing collaborative activities with the Fragile X Clinical & Research Consortium.
- (2) **Report language and increased resources for Fragile X at the National Institutes of Health (NIH)** to:
  - Support continued implementation of the recommendations outlined in the NIH Fragile X-associated Disorders Research Blueprint as well as increased NIH support for the Fragile X Clinical & Research Consortium.
  - Enhance its efforts across its Institutes to translate basic science findings into viable treatments for Fragile X, and encourage clinical drug trials for this orphan indication.
  - Maximize Fragile X resources by ensuring that appropriate resources and direction is provided to implement the objectives outlined in the Fragile X Research Blueprint.
  - Strengthen and broaden research on Fragile X-associated disorders (i.e., Fragile X-associated tremor/ataxia syndrome (FXTAS) and Fragile X-associated primary ovarian insufficiency (FXPOI)).

Furthermore, as part of our overall to increase support and prioritization of Fragile X-associated Disorders at the federal level, the Fragile X community is also working with the Defense Subcommittee on Appropriations to include Fragile X-associated Disorders among the list of eligible healthcare conditions for targeted biomedical research funding through the U.S. Department of Defense. The success from all of these intense public and private research efforts, including the NIH and CDC, has brought discoveries to bear for Fragile X-associated Disorders. However, we feel continued expansion of federal efforts and resources at each of these agencies will be instrumental to conduct promising research on Fragile X-associated Disorders.

Mr. Chairman, thank you for your time and attention. We, at the National Fragile X Foundation, believe that continued awareness and support for enhancing Fragile X research and translational activities is imperative. Given the significant impact this condition has on families and communities

across the country, the promise of a breakthrough for the treatment and cure of this disease is urgent. Should you have any questions or require additional information, please feel free to call on me.

**Fiscal Year 2010 Appropriations Request**

**House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, Education, and  
Related Agencies**

**May 1, 2009**

**Testimony for the Printed Record**

**Adrienne Breidenstine  
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***The National Health Care for the Homeless Council respectfully asks the House Committee on Appropriations to strengthen and expand the nation's health centers by appropriating \$2.9 billion for the Consolidated Health Centers Program in Fiscal Year 2010.***

**The National Health Care for the Homeless Council** is a membership organization engaged in education and advocacy to improve health care for homeless persons and all Americans. We represent 111 organizational members, including 100 Health Care for the Homeless projects, and over 700 individuals who provide care to people experiencing homelessness throughout the country.

**Homelessness & Health:** Poverty, lack of affordable housing, and the lack of comprehensive health insurance are among the underlying structural causes of homelessness. For those struggling to pay for housing and other basic needs, the onset of a serious illness or disability easily can result in homelessness following the depletion of financial resources. The experience of homelessness causes poor health, and poor health is exacerbated by restricted access to appropriate health care – which only prolongs homelessness. Additional barriers to health care access include lack of transportation, inflexible clinic hours, complex requirements to qualify for public health insurance, and mandatory unaffordable co-payments for various services.

Mainstream health care safety net providers often fail to meet the needs of homeless people. In the absence of universal health care, the Federal government supports a separate health care system for low-income and uninsured people. Community Health Centers and publicly funded mental health and addictions programs form the core of this health care safety net. Unfortunately, limited resources, lack of experience with this population, and insufficient linkages to a full range of health and supportive services

seriously restrict the ability of mainstream providers to meet the unique needs of people experiencing homelessness.

**The Federal Health Care for the Homeless Program**—administered by the Health Resources and Services Administration (HRSA)—currently supports 205 HCH projects in all 50 states, the District of Columbia, and Puerto Rico. Congress established Health Care for the Homeless (HCH) in 1987 to provide targeted services for people experiencing homelessness, including primary and behavioral health care along with social services, as well as intensive outreach and case management to link clients with appropriate resources. Approximately 70% of those served by HCH projects lack comprehensive health insurance. The HCH program has been reauthorized three times, most recently in 2008 with passage of the Health Care Safety Net Act. HCH projects served 742,588 in 2007— a sizable number, but far below the 3.5 million Americans who annually experience homelessness. Authorizing language designates 8.7% of the total Health Center appropriation to support the HCH program.

**Community Health Centers:** Over the past several years, the expansion of community health centers has received bipartisan support from Members of Congress. Federally-Qualified Health Centers (FQHCs) consistently have proven their effectiveness in delivering comprehensive medical care to underserved populations. Though health centers currently serve more than 16 million people annually, at least 56 million Americans—both insured and uninsured—face inadequate access to primary care due to a shortage of physicians and other providers. Without sufficient access to care, the health problems of the insured and underinsured are exacerbated, resulting in costly treatment, medical complications, and even premature death.

Within the current economic context, a massive unmet need remains for health center resources despite years of incremental expansion through the Health Center Growth Initiative. The deteriorating economy leaves more Americans unemployed, at risk of homelessness, and in need of health services. According to the Department of Labor, unemployment jumped to 8.5% in March 2009, the highest in 14 years. With continued increases in unemployment, more Americans are expected to lose health coverage, thus placing additional burden upon community health centers.

**Fiscal Year 2010 Appropriations:** In recognition of the growing need for primary health care services, the House Committee on Appropriations along with other Members of Congress has been supportive of strengthening and expanding community health centers. In the current year, Congress appropriated \$2.2 billion – \$125 million above the FY 2008 appropriation. This included \$56 million in base grant adjustments and provided a total of \$191 million (8.7%) for the HCH program.

To continue strengthening the nation's health center infrastructure, we encourage the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Other Related Agencies to appropriate \$2.9 billion for the Community Health Center program (including \$252 million for the HCH program) in FY 2010. The National Council's request is consistent with planned increases outlined in the *Access for All America Act* (S. 486). This important legislation, introduced by

Senator Bernie Sanders, would quadruple the amount of funding for community health centers over the next five years.

The National Council applauds Congress for its strong support of community health centers. We thank Chairman Obey and the House Committee on Appropriations Subcommittee on Labor, Health and Human Service, Education, and Other Related Agencies for your consideration of this testimony.



**National League  
for Nursing**

**Testimony Regarding Fiscal Year 2010 Appropriations for  
Title VIII Nursing Workforce Development Programs  
May 1, 2009**

**Submitted by:** National League for Nursing

**To:** Subcommittee on Labor, Health & Human Services, Education, and Related Agencies,  
Committee on Appropriations, U.S. House of Representatives

**Agency Addressed:** Health Resources and Services Administration

The National League for Nursing (NLN) represents leaders in nursing education and nurse faculty across all types of nursing programs in the United States – doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical. With more than 1,200 nursing school and health care agency members, 30,000 individual members, and 21 regional constituent leagues, the NLN is the premiere organization dedicated to excellence in nursing education and preparing the nursing workforce to meet the needs of our diverse populations in an ever-changing health care environment. The NLN appreciates the opportunity to submit testimony examining nursing education and *urges the Subcommittee to fund the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) at \$215 million in FY 2010.*

Nursing education, fundamental to the infrastructure that delivers quality, cost-effective health care, has received emergency funding via the American Recovery and Reinvestment Act (P.L. 111-5), and an increase to \$171.031 million for the nursing Title VIII programs in the FY 2009 Omnibus Appropriations bill (P.L. 111-8). The NLN applauds the Subcommittee's efforts to develop a health policy that provides high-value care for every dollar invested in capacity building for the education of a 21st century nurse workforce. Yet, investments fall short of the health care reality facing our nation. Whereas health is fundamental to the country's stability and advancement, disparities in health outcomes are consequential to nurse educators and are integral to the NLN's core values. The NLN is worried that the nation's health demands are intensifying in our current economic situation, and that absent consistent support of and emphasis on a high-priority infrastructure, the recent boosts to Title VIII will not fulfill the intended expectation of paying down on asset investments in the front-line that generates quality health outcomes, the nurse workforce.

#### **THE NURSE PIPELINE AND EDUCATION CAPACITY**

Subcommittee members likely are aware that today's nursing shortage in their respective congressional districts is not insignificant. Reported in 2007 by the American Hospital Association, 116,000 more registered nurses (RNs) were needed in hospitals across the nation to fill immediate vacancies. The vacancy report seems to contrast with some recent news stories about freshly minted nursing school graduates unable to find employment in certain regions of the country. Hospital hiring freezes caused by the current economic downturn appear to be masking the reality of a persistent, and projected, shortage of nurses. This disconnect underscores the importance of heeding the call for



comprehensive health care reform as part of the economic solution. Policy makers must not lose sight of the overall growing demand for nurses in spite of local reports of oversupply.

According to the U.S. Bureau of Labor Statistics (BLS), the nurse workforce is the predominant occupation in the health care industry. The BLS numbers show the present nurse workforce at well over four times the size of the medical workforce, and the BLS occupational employment projections indicate that RNs will experience the largest increase in new jobs, among professional and related occupations, with a growth of 23 percent in employment change between 2006 and 2016.

The NLN's *Nursing Data Review 2006-2007: Baccalaureate, Associate Degree, and Diploma Program* casts a wide net on all types of nursing programs, from doctoral through diploma, to determine rates of application, enrollment, and graduation. The survey creates a true picture of nursing education, contributing to an exact understanding of the importance of the nursing workforce today and of the dimension of the challenges continuing into tomorrow. Key findings of the data review include:

- **Demand for spots in nursing programs continues to outstrip supply dramatically.** An estimated 99,000 qualified applications – or almost 40 percent of qualified applications submitted to prelicensure RN programs – were rejected in 2006-07.
- **Admissions have grown.** Associate degree in nursing (ADN) programs admitted 12.3 percent more new students than last year. Baccalaureate admissions continued to grow as well albeit at a slower rate (5.6 percent in 2006-07) than in recent years. Diploma admissions were down slightly (4.2 percent).
- **Enrollments jumped.** Driven by an increase in ADN enrollment, the nation's ranks of prelicensure nursing students grew by almost 20,000, or 6.7 percent between 2006 and 2007. By contrast, BSN programs did not change significantly during this period.
- **Graduation rates slowed in 2007.** Prelicensure graduations increased by only 3 percent between 2006 and 2007 after two years of more than 8 percent annual growth. Associate degree graduations accounted for the larger share of the increase, rising by 4.3 percent. Growth in baccalaureate program graduations slowed to only 2.3 percent, after a dramatic rise of almost 20 percent last year.

#### NURSE SHORTAGE AFFECTED BY FACULTY SHORTAGE

The NLN research provides evidence of a strong correlation between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new RNs. Increasing the productivity of education programs is a high priority in most states, but faculty recruitment is a glaring problem that likely will grow more severe. Without faculty to educate our future nurses, the shortage cannot be resolved.

Nurse faculty vacancies were described as acute by the NLN in its 2006 research, *Nurse Educators 2006: A Report of the Faculty Census Survey of RN and Graduate Programs*. Three years ago, there was an indication that the nurse faculty vacancies in the nation were growing. The estimated number of budgeted, unfilled, full-time positions countrywide in 2006 was 1,390. Then in one year, the NLN *Nursing Data Review 2006-2007* showed an appreciable rise in the vacancy situation. The study reported that nationwide more than 1,900 unfilled full-time faculty positions existed in

2007, affecting over one-third (36 percent) of all schools of nursing, with 84 percent of nursing schools attempting to hire new faculty in 2007-2008. Of those, 79 percent found recruitment "difficult" and almost one in three schools found it "very difficult." The two main difficulties cited were "not enough qualified candidates" (cited by 46 percent of schools), followed by inability to offer competitive salaries (cited by 38 percent). While graduations in the 2008-2009 school year from master's and doctoral programs in nursing rose by 12.8 percent (or 1,918 graduates) and 4.5 percent (or 24 graduates), respectively, projections still demonstrate a shortage of nurse faculty.

#### GENDER/RACE/ETHNIC DIVERSITY LIMITS FACULTY CAPACITY

The present nurse faculty staffing deficit is expected to intensify as the existing nurse educator workforce reaches retirement age. A 2006 *NLN/Carnegie Foundation Preparation for the Professions Program* national survey of nurse educators found that with 48 percent of nurse faculty over the age of 55, fully one-half of today's nurse faculty workforce is expected to retire by 2015, while just over one in five (21 percent) expect to retire within the next five years. The NLN/Carnegie data also distinguished the nurse faculty cohort from the rest of the academic workforce by age: Where 48 percent of nurse educators are age 55 and over, only 35 percent of U.S. academics and only 29 percent of health science faculty are over the age of 54.

Untapped resources of talent, from which schools of nursing could nurture replacements for retiring experienced faculty, are minority populations among the nurse faculty workforce: males and under-represented racial-ethnic groups. Data indicate the nurse faculty workforce largely remains homogenous, not reflective of the nation's population or of the nursing student population. In 2007, the percentage of male graduates from prelicensure RN programs held steady at 12 percent from 2006. Although the prelicensure RN programs' class of 2006 had been considerably more diverse than in previous years, 2007 brought little change in the percentage of racial-ethnic minorities graduating. Fewer than 23.6 percent of new graduates were from minority backgrounds in 2007 compared with 24.5 percent in 2006. These numbers contrast adversely to our nation, which is enriched by cultural complexity where 34 percent of our population identifies as racial and ethnic minorities.

The *NLN/Carnegie* study affirmed that 96 percent of nurse faculty are female, compared to the three-fifths of the U.S. postsecondary faculty who are males. Noting that the underrepresentation of racial and ethnic minorities among nurse educators "may be attributed to discrimination or socioeconomic disparities that impinge disproportionately upon minority groups trying to enter a high-skill occupation", the 2006 study nonetheless reports, "nursing also lags significantly behind the remainder of academia with respect to diversity." Seven percent of nurse educators are minorities, and "16 percent of U.S. faculty belong to a racial minority group."

The homogeneity of the nurse faculty plays out as a unique capacity constraint limiting nursing schools' ability to provide culturally appropriate health care education to develop a health care system that understands and addresses the needs of the nation's rapidly diversifying population. Factors such as biases and stereotyping, communication barriers, cultural sensitivity/competence, and system and organizational determinants contribute to health care disparities, generating a compelling need for workforce diversity.

## THE FEDERAL FUNDING REALITY

Today's undersized supply of appropriately prepared nurses and nursing faculty does not bode well for our nation, where the shortages are deepening health disparities, inflated costs, and poor quality of health care outcomes. The Title VIII Nursing Workforce Development Programs are a comprehensive system of capacity-building strategies to develop nurses by providing schools of nursing with grants to strengthen programs through such activities as faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, and loans, scholarships and services that enable students to overcome obstacles to completing their nursing education programs. Yet, as the HRSA's Title VIII data show, Congress must step up and provide more funding to address seriously this ongoing systemic problem of shortages.

**Nursing Education Loan Repayment Program (NELRP)** – In FY 2007, NELRP received 4,711 eligible applications and made 315 initial (2-year) awards and 271 amendment (3-year) awards. Whereas, in FY 2008, NELRP received 6,078 eligible applications and made 232 initial (2 year) awards and 203 amendment (3 year) awards.

**Nursing Scholarship Program (NSP)** – In FY 2007, 4,894 eligible applications were submitted to the NSP, and 172 applicants were selected to receive scholarship awards. Similarly, in FY 2008, the NPS turned away most of the applicants, resulting in the distribution of only 169 student awards.

**Advanced Education Nursing (AEN) Program** – In FY 2007, the AEN grants supported 5,978 nursing students across the advanced practice specialties. Only 3,419 graduate nursing students were assisted via AEN awards in FY 2008.

As the only organization that collects data across all levels of the nursing education infrastructure, the NLN can state with authority that the nursing shortage in this country will not be reversed until the concurrent shortage of qualified nurse educators is addressed. The Subcommittee's commitment to building an environment that prepares a qualified health care workforce composed of broad-based, inter-professional partnerships will help ensure better health, deliver measurable improvements, narrow the health inequalities gap, and with time, potentially lower health care costs for everyone in our nation. Without national efforts of some magnitude to match the health care reality facing our country today, a calamity in nurse education and in health care generally may not be avoided. The NLN urges Congress to *strengthen existing Title VIII Nursing Workforce Development Programs by funding them at a level of \$215 million for FY 2010.*

Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care.

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**TESTIMONY OF  
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**SUBMITTED TO THE HOUSE OF REPRESENTATIVES  
APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION AND RELATED AGENCIES  
REGARDING FY10 APPROPRIATIONS FOR THE DEPARTMENT OF  
HEALTH AND HUMAN SERVICES**

**MAY 1, 2009**

Chairman Obey and Ranking Member Tiahrt, thank you for the opportunity to submit testimony regarding the FY2010 budget for the National Heart, Lung and Blood Institute, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and the Centers for Disease Control and Prevention. The National Marfan Foundation is grateful for the Subcommittee's strong support of the NIH and CDC, particularly as it relates to life-threatening genetic disorders such as Marfan syndrome. Thanks in part to your leadership we are at a time of unprecedented hope for our patients.

It is estimated that 200,000 people in the United States are affected by Marfan syndrome or a related condition. Marfan syndrome is a genetic disorder of the connective tissue that can effect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome is a weakening of the aorta. The aorta is the largest artery carrying oxygenated blood from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Early surgical intervention can prevent a dissection and strengthen the aorta and the aortic valves. If preventive surgery is performed before a dissection occurs, the success rate of the procedure is over 95%. If surgery is initiated after a dissection has occurred, the success rate drops below 50%. Aortic dissection is a leading killer in the United States, and 20% of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication.

Fortunately, new research offers hope that a commonly prescribed blood pressure medication might be effective in preventing this frequent and devastating event.

### **NATIONAL HEART, LUNG AND BLOOD INSTITUTE**

#### **A) Pediatric Heart Network Clinical Trial**

NMF applauds the National Heart, Lung and Blood Institute for its leadership in advancing a landmark clinical trial on Marfan syndrome. Under the direction of Dr. Lynn Mahoney and Dr. Gail Pearson, the Institute's Pediatric Heart Network has spearheaded a multicenter study focused on the potential benefits of a commonly prescribed blood pressure medication (losartan) on aortic growth in Marfan syndrome patients.

NHLBI Director Dr. Elizabeth Nabel describes this promising research well.....

*"After the discovery that Marfan syndrome is associated with the mutation in the gene encoding a protein called fibrillin-1, researchers tried for many years, without success, to develop treatment strategies that involved repair or replacement of fibrillin-1. Then a major breakthrough occurred with the discovery that one of the functions of fibrillin-1 is to bind to another protein, TGF-beta, and regulate its effects. After careful analysis revealed aberrant TGF-beta activity in patients with Marfan syndrome, researchers began to concentrate on treating Marfan syndrome by normalizing the activity of TGF-beta. Losartan, which is known to affect TGF-beta activity, was tested in a mouse model of Marfan syndrome and the results showed that drug was remarkably effective in blocking the development of aortic aneurysms, as well as lung defects associated with the syndrome.*

*Based on this promising finding, the NHLBI Pediatric Heart Network, has undertaken a clinical trial of losartan in patients with Marfan syndrome. About 600 patients aged 6 months to 25 years will be enrolled and followed for 3 years. This development illustrates the outstanding value of basic science discoveries, and identifying new directions for clinical applications. Moreover, the ability to organize and initiate a clinical trial within months of such a discovery is testimony to effectiveness of the NHLBI Network in providing the infrastructure and expertise to capitalize on new findings as they emerge."*

Dr. Hal Dietz, the Victor A. McKusick Professor of Genetics in the McKusick-Nathans Institute of Genetic Medicine at the Johns Hopkins University School of Medicine, and the director of the William S. Smilow Center for Marfan Syndrome Research, is the driving force behind this groundbreaking research. Dr. Dietz uncovered the role that fibrillin-1 and TGF-beta play in aortic enlargement, and demonstrated the benefits of losartan in halting aortic growth in mice. He is the reason we have reached this time of such promise and NMF is proud to have supported Dr. Dietz's cutting-edge research for many years.

NMF is also proud to actively support the losartan clinical trial in partnership with the Pediatric Heart Network. Throughout the life of the trial we will provide support for patient travel costs, coverage of select echocardiogram examinations, and funding for ancillary studies. These ancillary studies will explore the impact that losartan has on other manifestations of Marfan syndrome.

**B) NHLBI "Working Group on Research in Marfan Syndrome and Related Conditions"**

In April 2007, NHLBI convened a "*Working Group on Research in Marfan Syndrome and Related Conditions*." Chaired by Dr. Dietz, this panel was comprised of experts in all aspects of basic and clinical science related to the disorder. The panel was charged with identifying key recommendations for advancing the field of research in the coming decade. The recommendations of the Working Group are as follows ---

"Scientific opportunities to advance this field are conferred by technological advances in gene discovery, the ability to dissect cellular processes at the molecular level and imaging, and the establishment of multi-disciplinary teams. The barriers to progress are addressed through the following recommendations, which are also consistent with Goals and Challenges in the NHLBI Strategic Plan. "

- Existing registries should be expanded or new registries developed to define the presentation, natural history, and clinical history of aneurysm syndromes.
- Biological and aortic tissue sample collection should be incorporated into every clinical research program on Marfan syndrome and related disorders and funds should be provided to ensure that this occurs. Such resources, once established, should be widely shared among investigators."
- An Aortic Aneurysm Clinical Trials Network (ACTnet) should be developed to test both surgical and medical therapies in patients with thoracic aortic aneurysms. Partnership in this effort should be sought with industry, academic organizations, foundations, and other governmental entities."

- The identification of novel therapeutic targets and biomarkers should be facilitated by the development of genetically-defined animal models and the expanded use of genomic, proteomic and functional analyses. There is a specific need to understand cellular pathways that are altered leading to aneurysms and dissections, and to develop robust in vivo reporter assays to monitor TGF $\beta$  and other cellular signaling cascades."
- The developmental underpinnings of apparently acquired phenotypes should be explored. This effort will be facilitated by the dedicated analysis of both prenatal and early postnatal tissues in genetically-defined animal models and through the expanded availability to researchers of surgical specimens from affected children and young adults."

We look forward to working closely with NHLBI to pursue these important research goals and ask the Subcommittee to support the recommendations of the Working Group. Mr. Chairman, for fiscal year 2010 NMF joins with other professional and patient organizations in recommending a 7% for NHLBI.

#### **NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES**

NMF is proud of its longstanding partnership with the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director and has generously supported several "Conferences on Heritable Disorders of Connective Tissue." Moreover, the Institute has provided invaluable support for Dr. Dietz's mouse model studies. The discoveries of fibrillin-1, TGF- $\beta$ , and their role in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS.

As the losartan clinical trial moves forward, we hope to expand our partnership with NIAMS to support related studies that fall under the mission and jurisdiction of the Institute. One of the areas of great interest to researchers and patients is the role that losartan may play in strengthening muscle tissue in Marfan patients. We would welcome an opportunity to partner with NIAMS in support of this research moving forward.

For FY10, NMF recommends a 7% increase for NIAMS.

**CENTERS FOR DISEASE CONTROL AND PREVENTION**

Mr. Chairman, we are grateful for the Subcommittee's encouragement in recent years of collaboration between CDC and the Marfan syndrome community. One of the most important things we can do to prevent untimely deaths from aortic aneurysms is to increase awareness of Marfan syndrome and related connective tissue disorders. Despite our ongoing efforts to raise awareness among the general public and health care providers, we know of too many families who have lost a loved one because of a missed diagnosis.

We are very appreciative of CDC's support of our 25<sup>th</sup> annual patient conference taking place in Rochester, MN August 6th – 9th, 2009. We have also discussed other potential collaborations with the National Center on Birth Defects and Development Disabilities focused on education and early diagnosis. We ask the Subcommittee to continue to encourage CDC to work with us to initiate these activities in fiscal year 2010.

For FY10, NMF joins with the CDC Coalition in recommending an appropriation of \$8.6 billion for core CDC programs.

**ABOUT THE NATIONAL MARFAN FOUNDATION**

The NMF is a non-profit voluntary health organization founded in 1981. NMF is dedicated to saving lives and improving the quality of life for individuals and families affected by the Marfan syndrome and related disorders. The Foundation has three major goals: (i) to provide accurate and timely information about the Marfan syndrome to affected individuals, family members, physicians and other health professionals; (ii) to provide a means for those with Marfan syndrome and their relatives to share in experiences, to support one another and to improve their medical care and (iii) to support and foster research.



National Melanoma Alliance

Written Testimony of Paula Kim

On behalf of the National Melanoma Alliance Submitted to the United States House of Representatives Committee on Appropriations- Fiscal Year 2010

The National Melanoma Alliance is dedicated to reducing the incidence and mortality of this cancer through awareness, education, and research. We seek to unify and leverage the strength of melanoma organizations throughout the country representing melanoma patients and their loved ones.

We thank you for allowing us to share our concerns with you regarding melanoma, the most commonly fatal form of skin cancer in our country. Let us highlight a little known fact that one person dies almost every hour from this preventable cancer. While we are pleased the death rates for other common cancers such as breast, colon, and prostate cancer are declining due to investments in prevention and research, death rates for melanoma have increased nearly 30% over the past 25 years.

**Prevalence of Skin Cancer:** There are over one million new cases of skin cancer diagnosed in the United States each year, outnumbering the total number of other cancers combined. Skin cancer includes the most serious skin cancer - melanoma, and the most common ones - basal cell carcinoma and squamous cell carcinoma.

**Mortality Rate:** Over ten thousand Americans die of skin cancer every year, 75% from melanoma. However, the potential for physical devastation from basal cell and squamous cell carcinomas must be recognized as well.

**The Cost of Skin Cancer:** There are significant emotional, physical, and financial costs associated with all forms of skin cancer. Newly diagnosed skin cancer in the US costs more than 1 billion dollars per year. However the emotional and physical costs are incalculable.

**Need for Increased Funding:** Research funding for the prevention of skin cancer has been disproportionately low. Skin cancer stands alone as the cancer for which incidence and mortality are rising unabated while the best means for combating the disease, prevention and early detection, continues to be severely underutilized.

Specifically, we respectfully request that you include the following items related to melanoma research and skin cancer prevention in the Fiscal 2010 Labor, Health and Human Services Appropriations bill:

- \$5 million for the skin cancer prevention activities of the Centers for Disease Control and Prevention in the Fiscal 2010 Labor, Health and Human Services Appropriations Bill;
- \$6 billion for the National Cancer Institute in the Fiscal 2010 Labor, Health and Human Services Appropriations Bill and language encouraging the National Cancer Institute to expand and better focus its melanoma research activities;
- Language encouraging the National Institute of Arthritis and

Musculoskeletal and Skin Diseases to expand and better focus its melanoma research activities in the Fiscal 2010 Labor, Health and Human Services Appropriations Bill

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<p><b>NPRCs</b>  <i>National Primate Research Centers</i></p> <p><i>Dallas Hyde</i>  <i>CNPRC Director</i>  <i>University of California, Davis</i>  <i>(530) 752-0420</i>  <i><a href="mailto:dmhyde@primate.ucdavis.edu">dmhyde@primate.ucdavis.edu</a></i></p>	<p><b>Written Statement for the Record Provided by the  Eight National Primate Research Center Directors</b></p> <p><b><i>Prepared for</i></b>  <b>Subcommittee on Labor/HHS/Education  and Related Agencies</b>  <b>Committee on Appropriations</b>  <b>United States House of Representatives</b>  <b>May 1, 2009</b></p>
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The Directors of the eight National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record to the U.S. House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. The NPRCs appreciate the commitment that the Members of this Subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH), and recommends that you maintain this support for NIH in FY 2010 by providing the agency with at least a 7 percent increase over FY 2009. The NPRCs also respectfully request that the Committee encourage the National Center for Research Resources (NCRR), the sponsoring institute of the NPRCs within NIH, to carry out the NPRCs five-year federal advancement initiative, which as explained in this testimony, would help to ensure that the NPRCs continue to serve effectively in their role as a vital national resource.

Through passage of the American Recovery and Reinvestment Act (ARRA) and the Omnibus Appropriations Act for FY 2009, the Administration and Congress have taken critical steps to jump start the Nation's economy. Simultaneously, Congress is advancing and accelerating the biomedical research agenda in this country by focusing on scientific opportunities to address public health challenges. The success of the U.S. Government's efforts, however, is contingent upon the quality of research resources that enable and enhance scientific research ranging from the most basic and fundamental to the most highly applied.

Biomedical researchers have relied on one such resource – the National Primate Research Centers – for nearly 50 years for research models and expertise with nonhuman primates. The NPRCs are highly specialized facilities that foster the development of nonhuman primate animal models and provide expertise in all aspects of nonhuman primate biology. NPRC facilities and resources are currently used by over 2,000 National Institutes of Health (NIH) funded investigators around the country. NCRR provides the NPRCs with an annual base grant (funded through NCRR's P51 program) which supports the operational costs of the NPRCs. In FY 2009, the eight NPRCs received \$79.235 million from NCRR's P51 program.

The NPRCs also serve an essential role in translating basic research toward a clinical outcome. Specifically, the nonhuman primate models that are housed at the NPRCs often provide the critical link between research with small laboratory animals and studies involving humans. As a result, the network of the eight NPRCs is taking a leadership role to encourage collaboration among researchers and health care providers across disciplines and institutions, with the goal of advancing biomedical knowledge and improving human health.

## NATIONAL PRIMATE RESEARCH CENTERS

The NPRCs face several serious barriers to successfully supporting and advancing nonhuman primate research; specifically, the lack of adequate infrastructure to breed and house animals for research, the limited number of primates available, and the shortage of properly trained staff to handle nonhuman primates and provide sophisticated care. The need to address these problems has become even more critical due to the additional nonhuman primate related grants that will be funded as a result of ARRA, the new demands to increase research in nonhuman primate challenge models for AIDS, and the need for nonhuman primates to enhance our emerging infectious disease and biodefense response capabilities.

NCRR has published on the need for increased primate resources in its 2009-2013 Strategic Plan. The plan specifically states that nonhuman animal models are indispensable for finding ways to treat and prevent cancer, HIV/AIDS, Alzheimer's disease, and Parkinson's disease, as well as to develop effective biodefense strategies. The NPRCs have been leading the development of new IT approaches, including the Biomedical Informatics Research Network (BIRN) for linking brain imaging, behavior, and molecular informatics in non-human primate preclinical and translational models research.

In an effort to address many of the concerns within the scientific community, ranging from the lack of infrastructure improvements to the shortage of relevant nonhuman primates to the need for quality, trained personnel, the NPRCs have developed a five-year federal advancement initiative which addresses the necessary program capacity expansions and required upgrades. This initiative will help to ensure that the NPRCs will continue to serve effectively in their role as a vital national resource. As part of the five-year plan development process, the NPRCs calculated the increases in NIH funding dedicated specifically to the National Primate Research Centers Program (NCRR's P51 program) necessary to achieve their goals. Below is an outline of the plan:

- **Primate Infrastructure Investment – Request for an additional \$90 million over five years to improve the quality and capacity of primate housing and breeding facilities and ensure availability of related state-of-the-art diagnostic and clinical support equipment at the NPRCs.**

While NIH has been responsive in their actions during the past few years to provide funding to the NPRCs for infrastructure improvements, the difficulty the National Primate Research Centers Program has in meeting even current demands, let alone future increases is inexorably linked to the ability to house these animals in the unique living environments that they require and to provide specialized facilities equipped with state-of-the-art diagnostic and clinical support equipment to conduct research. The NPRCs plan to focus on the following goals in their effort to comprehensively improve primate infrastructure:

- 1) Bring older primate housing facilities and related equipment up to present-day standards.
- 2) Construct additional primate housing facilities and acquire related equipment to accommodate the projected increase in breeding colonies.

## NATIONAL PRIMATE RESEARCH CENTERS

- **Primate Model Investment – Request for an additional \$75 million over five years to enhance the availability of primates for research.**

NCRR's Expert Panels have repeatedly stated that the NPRCs do not have the capacity to satisfy the needs of outside investigators, and have recommended that the NPRCs program must be responsive to national needs for nonhuman primates. Currently, outside investigators who are already funded for their studies must sometimes wait a year or more to begin their research because of the high demand for the limited number of primates. In addition, there are ongoing difficulties associated with acquiring certain types of primates from their natural places of origin. Accordingly, increasing domestic breeding capabilities and developing bridging programs to effectively use other types of primates are critical to the success of the NPRCs program.

- **Primate Care and Research Personnel Investment – Request for an additional \$35 million over five years to train NPRC personnel in primate care and management.**

Numerous scientific reports have highlighted the vital need for experts who are well trained in laboratory animal medicine and in research methodology. Since nonhuman primates represent the most sophisticated and relevant animal models, there is a heightened responsibility to properly care for and manage these animals. Each NPRC requires a primate management team comprised of behaviorists, veterinarians, and primate research specialists. As the number of primates at the NPRCs grows, the primate management teams must expand proportionally.

***Total Anticipated Cost of the National Primate Research Centers Program Five Year Federal Advancement Initiative – \$200 million over the current funding that is dedicated specifically to the National Primate Research Centers Program during the five year period of fiscal years 2010 - 2015.***

Thank you for the opportunity to submit this written testimony and for your attention to the critical need for primate research and enhancement of the NPRCs P51 base grant, as well as our recommendations concerning funding for NIH in the FY 2010 Appropriations bill.

Sincerely,

**California NPRC**  
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University of California

**Tulane NPRC**  
Andrew Lackner, DVM, PhD  
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John VandeBerg, PhD  
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National Psoriasis Foundation  
Written Testimony to the House Labor-Health and Human Services (LHHS)  
Appropriations Subcommittee  
Regarding Fiscal Year 2010 Psoriasis and Psoriatic Arthritis Research Funding  
Submitted by: Dale White, Chair, Board of Trustees,  
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May 1, 2009

### **Introduction and Overview**

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written testimony for the record regarding federal funding for psoriasis and psoriatic arthritis research for fiscal year (FY) 2010. The Foundation serves as the nation's largest patient-driven, non-profit, voluntary association committed to finding a cure for psoriasis and psoriatic arthritis, which affects as many as 7.5 million Americans, and eliminating their devastating effects. Psoriasis, is among the most prevalent autoimmune diseases.

As part of our mission, we educate health professionals, the public and policymakers to increase public awareness and understanding of the challenges faced by people with psoriasis and psoriatic arthritis. Moreover, the Foundation maintains a strong commitment to securing public policies and programs that support its focus of education, advocacy and research toward better treatments and a cure. The Foundation specifically seeks to advance public and private efforts to improve treatment of these diseases, identify a cure and ensure that all people with psoriasis and psoriatic arthritis have access to the medical care and treatment options they need to live the highest quality of life possible.

The Foundation stands ready to partner with policymakers at the local, state and federal levels to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. Specifically, the Foundation advocates that in FY 2010 the National Institutes of Health (NIH) receive an additional \$2.1 billion for a total allocation of \$32.5 billion to support new investigator-initiated research grants for genetic, clinical and basic research related to the understanding of the cellular and molecular mechanisms of psoriasis and psoriatic arthritis, as well as studies to explore the nascent understanding of co-morbidities, such as obesity, depression and heart disease that may be associated with inflammation in the skin and joints. In addition, we urge that Congress provide \$1.5 million in FY 2010 to the Centers for Disease Control and Prevention (CDC) to support such data collection to increase understanding of the comorbidities associated with psoriasis, examine the relationship of psoriasis to other public health concerns, such as the high rate of smoking and obesity among those with the disease, and gain insight into the long-term impact and treatment of these two conditions.

### **The Impact of Psoriasis and Psoriatic Arthritis**

According to the NIH, as many as 7.5 million Americans have psoriasis – an immune-mediated genetic, chronic, inflammatory, painful, disfiguring and life-altering disease that requires life-long sophisticated medical intervention and care, and imposes serious adverse effects on the

individuals and families affected. On average, 17,000 people with psoriasis live in each Congressional District.

Psoriasis typically first strikes between the ages of 15 and 25, but can occur at any time. It lasts a lifetime. Unfortunately, psoriasis often is overlooked or dismissed, because it typically does not cause death. It is commonly and incorrectly considered by insurers, employers, policymakers and the public as a mere annoyance – a superficial problem, mistakenly thought to be contagious and/or due to poor hygiene. Yet, together psoriasis and psoriatic arthritis impose significant economic costs on individuals and society. Total direct and indirect health care costs of psoriasis are calculated at over \$11,250,000,000 annually with work loss accounting for 40 percent of the cost burden.

There is mounting evidence that people with psoriasis are at elevated risk for myriad other serious, chronic and life-threatening conditions. Although data are still emerging on the relationship of psoriasis to other diseases and their ensuing costs to the medical system, it is clear that psoriasis goes hand-in-hand with co-morbidities, such as Crohn's disease, diabetes, metabolic syndrome, obesity, hypertension, heart attack, cardiovascular disease, liver disease and psoriatic arthritis – which occurs in up to 30 percent of people with psoriasis. Other recent studies have found that people with severe psoriasis have a 50 percent higher mortality risk and that these patients die three to six years younger than those who do not have psoriasis. Of serious concern is that studies have shown that psoriasis causes as much disability as other major chronic diseases, and individuals with psoriasis are twice as likely to have thoughts of suicide, as people without psoriasis or with other chronic conditions.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of improved quality of life and effective, safe, and affordable therapies, which could be delivered through an increased federal commitment to genetic, clinical and basic research. Research holds the key to improved treatment of these diseases, better diagnosis of psoriatic arthritis and eventually a cure for both conditions.

#### **Federal Psoriasis and Psoriatic Arthritis Research**

Although overall NIH funding levels improved for psoriasis research in FY 2007, three out of five NIH agencies decreased psoriasis funding that same year. The Foundation is concerned that at the historical and current rate of psoriasis funding, NIH funding is not keeping pace with research needs, nor is the investment commensurate with the impact of the disease. Within the NIH, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Center for Research Resources (NCRR), the National Human Genome Research Institute (NHGRI) and the National Institute of Allergy and Infectious Diseases (NIAID) are the principal federal government agencies that currently support psoriasis research. Additionally, research activities that relate to psoriasis or psoriatic arthritis also have been undertaken at the National Cancer Institute (NCI). An analysis of longitudinal federal funding data shows that, on average over the past decade, NIAMS has spent less than \$1 per person with psoriasis per year.

Adequate investment in psoriasis and psoriatic arthritis in FY 2010 and beyond is imperative, because a rare opportunity for breakthroughs in both conditions is presenting itself at this time. A convergence of findings reached through various types of studies has stimulated new ideas about the mechanisms involved in psoriasis.

It has taken nearly 30 years to understand that psoriasis is not solely a disease of the skin, but also of the immune system. Finally, scientists are identifying the genes immune cells involved in psoriasis – findings that will help improve understanding of which cells or molecular processes should be targeted in psoriasis drug development. With these important advances, we are poised and positioned, as never before, to identify and develop a permanent method of control for psoriasis and, eventually, a cure. Greater funding of genetics, immunology and clinical research focused on understanding the mechanisms of psoriasis and psoriatic arthritis is needed. Key areas for additional support and exploration include:

- **Studying the genetic susceptibility of psoriasis.** Although great progress has been achieved recently with identification of several susceptibility genes for psoriasis and the completion of the first step of the largest genetic study on psoriasis susceptibility performed so far (e.g., the Genetic Association Information Network study), more support is needed. The identified susceptibility genes need to be confirmed in follow-up studies or other independent studies. Additionally, new initiatives are needed to elucidate how these genes lead to psoriasis and psoriatic arthritis. These studies will enhance understanding of the causes of psoriasis and psoriatic arthritis and may answer the question why some individuals respond positively to specific drugs while others do not.
- **Developing animal models of psoriasis.** Psoriasis is uniquely limited to the human species. This lack of animal models has considerably slowed the pace of progress in psoriasis research over the past couple of decades. With increased understanding of the molecular processes and susceptibility genes involved in psoriasis, creation and use of animal models will play a major role in psoriasis research in the future and may greatly accelerate progress towards treatment or cure.
- **Identifying the environmental and lifestyle triggers for psoriasis.** Psoriasis commonly is classified as a complex disease, meaning that it has several genetic factors, each independently conferring low risk, along with specific, although not yet fully defined, environmental agents that can trigger the onset of the disease. Examining the relationship between the genes and the environment will further our understanding of the disease and may lead to new treatments and preventive measures against developing psoriasis.
- **Studying a number of important epidemiologic issues, such as the risk of heart attack, diabetes, increased mortality and lymphoma in psoriasis patients.** Longitudinal studies are needed to learn about key attributes, such as whether more effective treatments lower these risks. Additionally, explaining the relationship between co-morbidities and psoriasis may shed light on shared molecular pathways and lead to development of new therapeutic targets.



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- **Identifying and examining immune cells and inflammatory processes involved in psoriasis.** The immune system is paramount in psoriasis. A new immune cell subset, T-helper 17 (Th17) cell, recently has been identified, and has been suggested to be a major contributor to psoriasis inflammation. Further study of this immune subtype and other branches of the immune system and identification of potential auto-antigens (evidence that psoriasis is an auto-immune disease) will greatly enhance understanding of the disease and may lead to eventual cure of the disease.
- **Examining the relationship between psoriasis and mental illnesses, such as depression and suicidal ideation.** Instruments are needed to measure the mental health impact of psoriasis and/or to validate those already available for this disease. It is also important to identify any underlying biologic reasons for mental health issues associated with psoriasis. Studying further how negative social and psychological effects impact psoriasis (e.g., does the psychological component worsen the psoriasis?) also is critically important.
- **Elucidating psoriatic arthritis specific genes and other biomarkers.** Approximately ten to thirty percent of people with psoriasis develop arthritis and, on average, the psoriasis precedes the arthritis by ten years. Isolation of such genes could help identify patients at risk for arthritis may provide an opportunity to intervene early in the disease course with therapies that may prevent or delay onset of joint inflammation and therefore later disability.

#### **The Role of CDC in Psoriasis and Psoriatic Arthritis Research**

The Foundation is concerned that there have been very few efforts to collect epidemiological and other related data on individuals with psoriasis and psoriatic arthritis. Researchers and clinicians continue to be limited in their longitudinal understanding of these conditions and their effects on individual patients. There are many mysteries related to psoriasis and psoriatic arthritis. For example, we know of people who never had any evidence of disease who, after falling ill with the flu or spiking a fever, wake the next day to be covered in psoriasis plaques. Why? A treatment could work well for an individual for years and then suddenly become ineffective. Why?

Researchers agree that collecting data through a patient registry would help increase the understanding of: the other chronic conditions that co-occur with psoriasis; how factors like age or gender impact the course and burden of psoriasis; and how certain environmental exposures might contribute to the occurrence and severity of psoriasis and psoriatic arthritis. In turn, this information would help improve treatments and advance efforts toward a cure. CDC psoriasis and psoriatic arthritis data collection efforts would help answer myriad questions about these autoimmune conditions, contribute to improved disease treatment and management, and further the nation's efforts to find a cure.

For three years, your Subcommittee has encouraged CDC to undertake data collection, and we very much appreciate your recognition of this much-needed effort. We have met with CDC staff to offer our assistance and expertise, however, it is clear the agency must receive specific,

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dedicated funding so it has the resources necessary to develop a registry. To that end, the Foundation respectfully requests that the Subcommittee allocate \$1.5 million in FY 2010 for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) within the CDC to examine and develop options and recommendations for the creation of a National Psoriasis and Psoriatic Arthritis Patient Registry. A national patient registry that collects longitudinal patient data will help researchers to learn about key attributes, such as response to treatment, substantiating the waxing and waning of psoriasis, understanding associated manifestations like nail disease and arthritis, and the relationship of psoriasis to other public health concerns.

#### **Funding Request Summary**

The Foundation recognizes that Congress and the nation face unprecedented fiscal challenges. However, we also believe that greater FY 2010 investment in biomedical and epidemiologic research at NIH and CDC will prove stimulative to the economy and bear fruit with regard to the development of new, safe, effective and long-lasting treatments and – ultimately – a cure for psoriasis and psoriatic arthritis. We thank the Subcommittee in advance for providing the following allocations:

- \$32.4 billion to NIH and its institutes and centers that play an integral role in psoriasis and psoriatic arthritis research and urge them to initiate and/or expand psoriasis and psoriatic arthritis research and;
- \$1.5 million to the NCCDPHP within the CDC to collect data on psoriasis and psoriatic arthritis and begin to establish a patient registry to improve the knowledge base of the longitudinal impact of these diseases on the individuals they affect.

#### **Conclusion**

On behalf of the Foundation's Board of Trustees and the as many as 7.5 million individual with psoriasis and psoriatic arthritis who we represent, thank you for this opportunity to submit written testimony regarding the FY 2010 funding levels necessary to ensure that our nation adequately addresses psoriasis and psoriatic arthritis and to make gains in improving therapies and eventually attaining a cure. We believe that additional research undertaken at the NIH coupled with epidemiologic efforts at the CDC together will help advance the nation's efforts to improve treatments and identify a cure for psoriasis and psoriatic arthritis. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to – and consideration of – our requests.

Statement of Vivian Schiller, President and CEO  
National Public Radio (NPR)  
May 1, 2009

**Subcommittee on Labor, Health and Human Services, Education and Related Agencies**  
**U.S. House Committee on Appropriations**  
Fiscal Year 2010 – 2012 Appropriations for the Corporation for Public Broadcasting

Thank you Chairman Obey and Representative Tiahrt for the opportunity to testify on behalf of National Public Radio (NPR), our more than 850 public radio station partners, and for other producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and many, many stations, both large and small, that create and distribute content through the Public Radio Satellite System (PRSS).

The state of public radio today is both sobering and heartening. While the economic crisis has undermined the financial stability of the public radio system, the audience is tuning at record levels. But without your help, we will not be able to continue to achieve our public service mission, and your expectations.

**An Additional Investment in Stations:**

Public Broadcasting is requesting \$307 million – \$96 million for public radio stations and \$211 million for public television stations – in additional emergency investment funding for the FY 2010 budget of the Corporation for Public Broadcasting (CPB). This action is necessary to offset the tide of losses at public broadcasting stations. This one-time investment of federal resources will help protect thousands of station jobs now at risk, and assure continuity in services used daily by tens of millions of Americans. These funds are in addition to the \$420 million that Congress approved two years ago as part of the advance funding process.

The funds we are requesting only partially close the expected two-year revenue shortfall of almost \$170 million at the public radio station level, plus an additional \$55 million in losses at NPR. The remainder will come about as a result of significant cost cutting at the local and national levels. Every week brings another announcement of a service reduction or employment layoff at public broadcasting stations. In fact, a survey last month of locally licensed and operated public radio stations projected more than a 46 percent reduction in financial support from local and state government agencies, a 23 percent decline in foundation and philanthropic contributions and a 23 percent drop in underwriting from local businesses.

Public broadcasting's contribution to America's democracy is more important today than at anytime during our four decades of public service. Over 33 million people each week are tuning into public radio programming and listening to member stations. Our audience has grown 66% in the past 10 years, bucking a precipitous decline in other media and stands in sharp contrast with the general overall decline in radio listening. Consider that public radio programming today reaches more people than the circulation of *USA Today*, the *Wall Street*

*Journal, the New York Times, Los Angeles Times, the Washington Post* and the next top 45 newspapers combined.

Stations in every state have become living embodiments of journalistic excellence, providing news, information and cultural programming that have become increasingly rare in other media. Public radio programming is rooted in the fundamentals of accuracy, transparency, independence, balance, and fairness and serves as cornerstone of understanding for millions of Americans seeking information, context and insight.

**Public Funds for Public Media:**

CPB is the primary public funding mechanism for public radio, accounting for roughly 12% of an average public radio station's annual budget. These funds help public broadcasting stations produce, purchase and distribute programming that sparks imagination and kindles thought about our world. Several stations specifically serve rural and minority communities including numerous African-American, Native American, Latino and multicultural licensees. In many cases, they are the sole local broadcasting service available. These critical federal funds allow all stations to continue serving the needs of public radio's 33 million weekly listeners, irrespective of their communities' location or financial status.

CPB's general appropriation is allocated according to a congressionally set formula that ensures the funds go directly to the people and organizations that create and deliver highly-valued programs and services. The public broadcasting community is urging Congress to appropriate \$542 million in two-year advanced funding for FY 2012 for CPB.

**The Public Radio Satellite System:**

As the public broadcasting community grapples with the financial crisis, we also remain committed to ensuring that the nation's public radio infrastructure continues to be robust and viable. This commitment requires a periodic investment by Congress in the Public Radio Satellite System (PRSS). This year, CPB is requesting \$27 million as the third and final installment of a three year request to renew and replenish the PRSS.

This system, originally built in 1979 with funds provided by this Committee, distributes 400,000 hours of programming, or 7 and a half billion listener hours each year. Every minute of every hour of public radio programming -- from NPR's *Morning Edition*, and *All Things Considered*, to American Public Media's *Marketplace* and *A Prairie Home Companion*, to Public Radio International's *This American Life* and *Capitol News Connection* -- is distributed by the PRSS. Quite simply, without the PRSS, there would be no public radio in the United States.

An important mission of the PRSS is to facilitate the cost-effective and efficient distribution of news, information, cultural and educational programming to this country's increasingly diverse population. As part of that mission, the PRSS provides satellite transmission services to distribute programming that targets un-served or under-served audiences from sources who meet certain criteria established by the NPR Board, including demonstrated financial need. PRSS is the indispensable distribution backbone for everything heard on public

radio. On behalf of all in public radio, I ask for your support of this critically important funding request.

**Digital Transition Funding:**

Change is rapidly occurring in over the air radio broadcasting, the last enclave of the old analogue world. As of today, more than 650 public radio stations had either completed or have nearly completed conversion to a digital signal, which improves the overall listener experience by enhancing audio quality; eliminating reception interference; and utilizing multiple audio programming channels, or multicasting. To continue supporting this necessary change in our basic broadcast technology, CPB is requesting \$40 million as part of its FY 2010 budget.

Digital broadcasting technology has enabled public radio stations to increase local services to their communities. Over 160 stations are multicasting - doubling and tripling their programming to broaden and expand the base of listeners. Many stations have created Spanish language channels to provide news, including through BBC Mundo. Stations serving Native American communities are providing tribal programming over the air and online. Local community events such as concerts, town hall meetings, committee hearings, legislative floor sessions and other government programming are broadcast live using HD radio technology. Listeners with HD radio receivers may view a variety of useful messages that scroll across radio display screens, including artist name and song title, emergency alerts, live weather and real-time traffic updates, local news, school closings and movie listings.

Digital technology using the internet and mobile platforms expands public radio programming and community services. Expansion and improvement of public radio websites and our digital connections with audiences remain a major priority. Public radio stations and public radio program producers are all expanding to new platforms, and in so doing bring broader, deeper and more varied content to our audiences. The impact is already being felt. News coverage of the U.S. Presidential Election resulted in record level traffic to public radio station websites and NPR.org in terms of both visitors and page views. Ten million visitors went each month to NPR.org during October and November 2008 to view 115 million pages during the same time period. And just this past week, public radios web sites became an essential platform for updated information on Swine flu.

Other Internet and mobile platform program distribution efforts using iPhone applications, for example, have gained wide acceptance among public radio listeners and brought a new generation of consumers to our coverage. Local public radio station and NPR podcasts have become very popular, with some 14 million downloads occurring each month. Podcasts offered by stations are expanding programming in areas such as science, poetry, music, arts, history, politics, international affairs and health. The audience may also now download interactive media such as photo slide shows, video, Web streams and audio of local news, music and programming on their local station Web site.

Audiences are visiting station Web sites with greater frequency for local news and community events. Online community calendars posted on station Web sites allow local organizations of all sizes and areas to list public events and reach a wide audience. Listeners

viewing station Web sites are connecting with local non-profit organizations to obtain information about special cultural activities, festivals, public health fairs, musical events, educational seminars, lectures, classes, and workshops. Station Web sites also increasingly have online music play lists allowing the audience to find information on music played at their local station. Web-based social-networking features are used to foster online communities to give listeners the opportunity to connect over common interests and passions by engaging in dialogue and sharing viewpoints about their lives.

We are confident in our ability to meet the needs of our audience and our ability to emerge from the current economic crisis more prepared and better structured. But we cannot do either without your help. We ask for your approval of CPB's funding requests, including the additional, emergency, one-time investment to stations of \$307 million in FY 2010.



**National Recreation  
and Park Association**

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**Written Testimony of Lois G. Finkelman, Chair, and Jodie Adams (CPRP), President,  
submitted for the record on behalf of The National Recreation and Park Association  
House Appropriations Subcommittee on Labor, Health and Human Services  
and Education  
Concerning Funding for the Centers for Disease Control and Prevention's  
Healthy Communities Program in the FY 2010 Labor-HHS-Education Appropriations Bill  
May 1, 2009**

Thank you Chairman Obey, Ranking Member Tiahrt, and other honorable members of the committee for this opportunity to submit written testimony on the importance of funding the Centers for Disease Control and Prevention's (CDC) Healthy Communities Program at an increased level in the FY 2010 Labor-HHS-Education Appropriations bill.

The National Recreation and Park Association (NRPA) is a national, non-profit organization with a mission of advancing parks, recreation and environmental conservation efforts that enhance the quality of life for all people. There are more than 6,500 public park and recreation agencies throughout the country, majority of which are members of NRPA. Our membership of more than 21,000 individuals is comprised of citizens as well as professionals from federal, local and state park and recreation agencies across the country.

Our nation currently faces an obesity epidemic that is claiming the lives of adults and children and causing health care costs to rise. As Congress works to reform our health care system and address this epidemic, we request increased funding for the CDC to include \$75 million in funding for the Healthy Communities program in the FY 2010 Labor-HHS-Education Appropriations bill.

NRPA appreciates the Subcommittee's work to combat chronic disease and obesity through the funding it has provided to the CDC. As you know, obesity significantly contributes to the development and severity of chronic diseases such as heart disease and diabetes which are two of the leading causes of death and disability in the United States. These diseases also cause major limitations in daily living for almost 1 out of 10 Americans or about 25 million people. Unfortunately, these diseases are affecting the lives of our nation's adults as well as our children. As a result of poor nutrition and a lack of physical activity, our nation's children have fallen prey to the obesity epidemic resulting in a radical increase in childhood obesity rates between 1980 and present day. According to the CDC, the obesity rate in children ages 6 to 11 doubled from 6.5 percent in 1980 to 17.0 percent in 2006; and tripled among those ages 12 to 19 to 17.6 percent during the same time period.

In addition to robbing adults and children of their quality of life, obesity and chronic disease also have a negative impact on our nation's economy. The Department of Health and Human Services has stated that the medical care costs of people with chronic diseases account for more than 75 percent of the nation's \$2 trillion medical care costs. More than 25 percent of the rise in medical costs between 1987 and 2001 has been attributed to obesity. Currently, obese and overweight adults cost the U.S. anywhere from \$69 billion to \$117 billion per year. Given the health implications and the fiscal hardship associated with chronic disease and obesity, we can no longer afford to be a nation that simply treats the problem.

In February, the President released his budget blueprint that stressed the importance of ensuring access to proven preventive interventions and the importance of prevention to our nation's economic vitality. Investment in prevention and wellness was one of President Obama's eight core principles guiding health care reform. Throughout the last several years, members of this Subcommittee have led efforts and sponsored legislation that would change the state of our current health care system from one that focuses on treating chronic disease to one that works to prevent the onset of chronic disease through combating obesity. Chronic disease and obesity have grown to the level of national epidemics as an offshoot of the problems that exist within individual communities. The only way to effectively prevent them and stop them from being national epidemics is to promote healthy lifestyles at the community level. This requires an organized effort to ensure communities have the tools and resources they need to influence positive behavior.

CDC recognizes the significant results that can be achieved through intervention at the community level as well as the importance of involving national partners, community organizations and community leaders in developing a strategy focused on prevention. CDC funds numerous programs at the national, state and local level that work to improve community health. Through its Healthy Communities program, CDC facilitates the collaboration of local and state health departments, national organizations with extensive reach into communities and a wide range of community leaders and groups to develop, activate and spread policy, systems and environmental changes that prevent chronic disease by changing the behavior that leads individuals to contract chronic diseases. Such policy, systems and environmental changes encourage people to be more physically active, improve nutrition, and abstain from tobacco use. To date, more than 240 communities have received funding and technical support through CDC's Healthy Communities Program, which has resulted in measurable changes at the local level. An additional 260 communities will receive funding to improve the health of their communities during the next five years.

The need to address these issues at the community level is very real. In Ithaca, New York, a 2001 survey of 8th grade students at a local middle school found that 21 percent of girls and 33 percent of boys were overweight or at risk for being overweight; and among those 15 percent were at risk for high blood pressure. The data also documented a need for more physical activity, especially moderate exercise. Many children are physically active only in school PE classes. However in the survey above, only 55 percent of girls and 67 percent of boys in 8th grade reported spending more than 20 minutes of an average PE class actually exercising.

Chicago, Illinois has noted that 26 percent of their children and 25 percent of their adult populations are obese by national standards. Contributing to the poor health of this community



is the lack of opportunities for physical activity and the fact that the west side of Chicago lacks grocery stores which has caused it to become a "food desert". This, in turn causes residents to utilize fast food chains and convenience stores as a main source of nourishment. Recognizing the health and financial implications of an obese population, Chicago is taking proactive steps to ensure a healthier a community. The park district has introduced new fitness classes in parks throughout the city and is now offering a minimum of 60 minutes of moderate to vigorous activity for all children's programs offered through parks. Through the leadership of the Mayor's office, a healthy vending policy has been initiated at all park facilities and the park district is implementing community produce gardens which will be maintained by local youth. Additionally, smoking has been banned on all Chicago Park District Property, indoors and out including beaches. Thanks to funding provided through CDC's Healthy Communities program, the city of Chicago will be able to implement more policy, systems and environmental changes, such as these, to combat chronic disease and obesity throughout the city.

These are just two examples of the abundance of issues that are facing communities and leading to a national epidemic of chronic disease and obesity. These two communities possess very unique problems. While other communities may face similar problems, change will require solutions that are unique to these individual communities. CDC's Healthy Communities program helps communities to develop their unique solutions. For this reason, CDC's Healthy Communities program is invaluable to improving the quality of life and helping to save the lives of Americans while protecting our nation's economy.

NRPA respectfully requests that the House Appropriations Subcommittee on Labor, Health and Human Services and Education provide increased funding for CDC in the FY 2010 Labor-HHS-Education Appropriations bill, which includes \$75 million in funding for CDC's Healthy Communities program.

Thank you for this opportunity to submit testimony. Please feel free to contact Stacey Pine, Chief Government Affairs Officer, in NRPA's Public Policy Office at 202-887-0290 with any questions you may have.

**Public Witness Testimony of Jill Kagan**  
**Chair, National Respite Coalition**  
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**For the House Subcommittee on Labor, HHS and Education Appropriations**  
**April 30, 2009**

Mr. Chairman, I am Jill Kagan, Chair of the ARCH National Respite Coalition, a network of respite providers, family caregivers, state and local agencies and organizations across the United States who support respite. Twenty-five state respite coalitions, including the Wisconsin Respite Care Association and the Kansas Lifespan Respite Coalition, are also affiliated with the NRC. This statement is presented on behalf of these organizations, as well as the members of the Lifespan Respite Task Force, a coalition of over 80 national and more than 100 state and local groups who supported the passage of the Lifespan Respite Care Act (P.L. 109-442). Together, we are requesting that the Subcommittee include funding for Lifespan Respite Care Program in the FY 2010 Labor, HHS and Education Appropriations bill at its modest authorized level of \$71.1 million for FY 10. This will enable:

- State replication of best practices in Lifespan Respite systems to allow all family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

Many Members of Congress already support funding for Lifespan Respite. We join the 12 Members of Congress who, along with Rep. Langevin (D-RI), recently sent a letter to the Subcommittee making this same request.

***Who Needs Respite?***

In 2004, a national survey found that 44 million family caregivers are providing care to individuals over age 18 with disabilities or chronic conditions (National Alliance for Caregiving (NAC) and AARP, 2004). AARP's most recent survey estimates that in 2007, about 34 million caregivers age 18 or older are providing an average of 21 hours of care per week to adults with limitations in daily activities. This estimation represents the number giving care at any given point. An even higher number, about 52 million, provided care at some point during the year (Gibson and Hauser, 2008). It has been estimated that these family caregivers provide \$375 billion in uncompensated care, an amount almost as high as Medicare spending (\$432 billion in 2007) and more than total spending for Medicaid, including both federal and state contributions and both medical and long-term care (\$311 billion in 2005) (Gibson and Hauser, 2008).

The overall number of family caregivers, when considering parents of children with disabilities is even larger. In 2006, the last year federal data were collected specifically for children with disabilities, 13.9 percent of US children (approximately 10 million) had special health care needs and 21% of households with children included at least one child with a special health care need. These rates represent a modest increase since the last survey conducted in 2001. (National Survey of Children with Special Health Care Needs, U.S. Health Resources and

Services Administration, 2008). Since the parents or other family members of these children are providing comprehensive long-term care for years or even decades, they should be considered family caregivers as well. These surveys suggest that a conservative estimate of the nation's family caregivers who provide significant amounts of care does indeed exceed 50 million.

Compound this picture with the growing number of caregivers known as the "sandwich generation" caring for young children as well as an aging family member. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition to a parent or other relative with a disability. And in the US, 6.7 million children, with and without disabilities, are in the primary custody of an aging grandparent or other relative..

The growing group most at risk for limited access to respite is the families of the wounded warriors – those military personnel returning from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions. A recent report from the Dept of Veterans Affairs at the Veterans Health Administration concluded: "Challenges remain, as the men and women who experience serious debilitating injuries, polytrauma, or traumatic brain injury (TBI) may require treatment spanning multiple healthcare systems and may need long-term care, personal assistance, and family support spanning decades."

To facilitate the transition from institutional care to the home and community and plan for the ensuing needs for long term services and supports for severely injured veterans of the current war, the Geriatrics and Extended Care Polytrauma Rehabilitation Task Force (GECPR) was established in May 2007. A major recommendation of the Task Force was to "Improve access to, and utilization of, respite services for younger veterans." (US Dept of Veterans Affairs, Veterans Health Administration, Report of the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force, February 2008) The National Respite coalition is currently serving on a VA Advisory group to help implement this recommendation.

Together, these family caregivers are providing an estimated 80% of all long-term care in the U.S. This percentage will only rise in the coming decades with an expected increase in the number of chronically ill veterans returning from war, greater life expectancies of individuals with Down Syndrome and other disabling and chronic conditions, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

#### ***What is Respite Need?***

State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers (Evercare and NAC, 2006). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the nation's family caregivers. The 2004 NAC/AARP survey of caregivers found that despite the fact that the most frequently reported unmet needs were "finding time for myself" (35%), "managing emotional and physical stress" (29%), and "balancing work and family responsibilities" (29%), only 5% of family caregivers were receiving respite (NAC and AARP, 2004). In rural areas, the percentage of family caregivers able to make use of respite dropped to 4% (Easter Seals and NAC, 2006). In a study of a nationally representative profile of noninstitutionalized children ages 0-17 year of age who were receiving support from the Supplemental Security Income (SSI) program because of a disability, only 8% reported using respite care but three quarters of families had unmet needs for respite (Rupp, K, et al, 2005-2006).

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even

when respite is an allowable funded service, a critically short supply of well trained respite providers may prohibit a family from making use of a service they so desperately need.

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. The 25 state coalitions and other National Respite Network members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm. A recent study conducted by the Family Caregiver Alliance identified 150 family caregiver support programs in all 50 states and Washington, DC funded with state-only or state/federal dollars. Most of the funding comes through the federal National Family Caregiver Support Program. As a result, programs are administered by local area agencies on aging, primarily serve the elderly, and provide only limited respite, if at all. Only about one-third of the 150 identified programs serve caregivers who provide care to adults age 18-60 who must meet stringent eligibility criteria. As the report concluded, "State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the states."

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. Three-fifths of family caregivers age 19-64 surveyed recently by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers (Ho, Collins, Davis and Doty, 2005). A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age (Schulz and Beach, December 1999).

Supports that would ease their burden, most importantly respite care, are too often out of reach or completely unavailable. Even the simple things we take for granted, like getting enough rest or going shopping, become rare and precious events. One Massachusetts mother of a seriously ill child spoke to the demands of constant caregiving: "I recall begging for some type of in-home support...It was during this period when I fell asleep twice while driving on the Massachusetts Turnpike on the way to appointments at Children's Hospital. The lack of respite...put our lives and the lives of everyone driving near me at risk."

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for. A mother of a 12-year-old with autism was denied additional respite by her state DD (Developmental Disability) agency because she was not a single mother, was not at poverty level, wasn't exhibiting any emotional or physical conditions herself, and had only one child with a disability. As she told us, "Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service."

For the millions of families of children with disabilities, respite has been an actual lifesaver. However, for many of these families, their children will age out of the system when they turn 21 and they will lose many of the services, such as respite, that they currently receive. In fact, 46% of U.S. state units on aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities. An Alabama mom of a 19-year-old-daughter with multiple disabilities who requires constant care recently told us about her fears at a respite summit in Alabama, "My daughter Casey has cerebral palsy, she does not communicate, she is incontinent she eats a pureed diet, she utilizes a wheelchair, she is unable to bathe or dress herself. At 5'5" and 87 pounds I carry her from her bedroom to the bathroom to bathe her, and back again to dress her.... Without respite services, I do not think I could continue to provide the

necessary long-term care that is required for my daughter...As I age, I do wonder how much longer I will be able to maintain my daily ritual as my daughter's primary caregiver."

Disparate and inadequate funding streams exist for respite in many states. But even under the Medicaid program, respite is allowable only through state waivers for home and community-based care. Under these waivers, respite services are capped and limited to narrow eligibility categories. Long waiting lists are the norm.

Respite may not exist at all in some states for adult children with disabilities still living at home, or individuals under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions. In Tennessee, a young woman in her twenties gave up school, career and a relationship to move in and take care of her 53 year-old mom with MS when her dad left because of the strain of caregiving. She went for years providing constant care to her mom with almost no support. Now 31, she wrote, "And I was young – I still am – and I have the energy, but – it starts to weigh. Because we've been able to have respite care, we've developed a small pool of people and friends that will also come and stand in. And it has made all the difference."

#### ***Respite Benefits Families and is Cost Saving***

Respite has been shown to be a most effective way to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A recent report from the US Dept of Health and Human Services prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007)

The budgetary benefits that accrue because of respite are just as compelling, especially in the policy arena. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save government long-term care programs thousands of dollars. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999)

Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (FY 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75%, physician visits decreased by 64%, and antibiotics use decreased by 71% (Mausner, S., 1995).

In the private sector, the most recent study by Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions (MetLife and National Alliance for Caregiving, 2006).

***Lifespan Respite Care Program Will Help***

The Lifespan Respite Care Act is based on the success of statewide Lifespan Respite programs in four states: Oregon, Nebraska, Wisconsin and Oklahoma. A new Arizona State Lifespan Respite program is up and running. Michigan passed state Lifespan Respite legislation in 2004 but has had the funding to implement the program.

Lifespan Respite, which is a coordinated system of community-based respite services, helps states use limited resources across age and disability groups more effectively, instead of each separate state agency or community-based organization being forced to constantly reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and the savings used to fund new respite services for families who may not currently qualify for any existing federal or state program.

The state Lifespan Respite programs provide best practices on which to build a national respite policy. The programs have been recognized by prominent policy organizations, including the National Conference of State Legislatures, which recommended the Nebraska program as a model for state solutions to community-based long-term care. The National Governors Association and the President's Committee for People with Intellectual Disabilities also have highlighted lifespan respite systems as viable solutions. And most recently, the White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress.

For the growing number of veterans returning home with TBI or other polytrauma, the shortage of staff qualified to provide respite to this population is especially critical. Lifespan Respite systems can make all the difference by ameliorating special barriers for this population.

The purpose of the law is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, states would be required to establish state and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services. Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

The federal Lifespan Respite program would be administered by the U.S. Department of Health and Human Services (HHS), which would provide competitive grants to statewide agencies through Aging and Disability Resource Centers working in collaboration with state respite coalitions or other state respite organizations. The program was authorized at \$53.3 million in FY 09 rising to \$95 million in FY 2011. Congress appropriated \$2.5 million for FY09, but these funds have not yet been obligated.

No other federal program mandates respite as its sole focus. No other federal program would help ensure respite quality or choice, and no current federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include \$71.1 million in the FY 10 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated in the states and more families, with access to respite, will be able to continue to play the significant role in long-term care that they are fulfilling today.

*Complete references available upon request. Prepared by Jill Kagan, Chair, National Respite Coalition, 4016 Oxford Street, Annandale, VA, 22003; 703-256-9578; [jbkagan@verizon.net](mailto:jbkagan@verizon.net); [www.archrespite.org](http://www.archrespite.org).*

**Written Testimony provided by Dr. Francis Eberle  
Executive Director  
National Science Teachers Association  
703-312-9214  
feberle@nsta.org**

**Before the  
House Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies  
Congressman David Obey, Chair  
Congressman Todd Tiahrt, Ranking Member  
May 1, 2009**

The National Science Teachers Association, the largest organization in the world promoting excellence and innovation in science teaching and learning for all, respectfully requests that the House Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies provide at least \$450 million in funding for the Math and Science Partnerships, the amount authorized for the program under Title II B of the No Child Left Behind Act.

As you know many efforts to increase student achievement are increasingly being focused on the teacher, since research tells us that the teacher is fundamental to student learning.

The Mathematics and Science Partnerships (MSP) program has been successful in improving teachers' content knowledge, classroom instruction, and student learning in science and mathematics. Administered by the U.S. Department of Education, the MSP program awards grants to each of the 50 states, the District of Columbia, and Puerto Rico, based on a formula derived from states' poverty rates and student population. After receipt of the funds, the states must then make grant awards, on a competitive basis, to partnerships that must include a high-need local educational agency, and engineering, mathematics or science (STEM) departments of institutions of higher education (IHE). Other partners may participate.

According to the U. S. Department of Education report *Mathematics and Science Partnerships Summary of the Fiscal Year 2006, Annual Reports, December 12, 2008*, in FY 2006, the Mathematics and Science Partnership program reached more teachers and students than ever before. Together, over 3,000 IHE faculty and approximately 3,800 organizations partnered to form 501 projects across the country. They provided over 49,000 hours of professional development to more than 56,000 teachers nationwide, thus enhancing the quality of classroom instruction for over two million students.

The majority (84 percent) of teachers who participated in MSP projects were elementary and middle school teachers. Sixty-five percent (65 percent) of projects provided summer institutes, with almost all of these projects providing follow-up throughout the school year. Of the projects that provided summer institutes with follow-up, teachers were provided an average of 125 hours of professional development; 66 hours during the summer and 59 hours during the school year.

The majority of projects (83 percent) used the individual teacher model. In this model, teachers from a set of schools or school districts participate as individuals in order to improve their own content knowledge and teaching skills in the effort to influence instruction in these teachers' classrooms, and thus contribute to their students' learning.

In the second model (17 percent), teachers are trained to become mathematics and science leaders in their schools. These projects provided teachers with content knowledge and leadership training, and expect that they, in turn, will provide professional development to other teachers in their schools or districts to help them improve their mathematics and/or science instruction.

The professional development activities, which included on-site professional development, study groups, content coursework at colleges or universities, online coursework, distance learning networks, workshops, and conferences, focused on increasing teachers' content knowledge in mathematics and/or in science, and on enhancing the teachers' pedagogical content knowledge skills.

According to the 2006 report, **71 percent of teachers participating in a MSP who were assessed in mathematics showed significant gains in their content knowledge and 80 percent of teachers who were assessed in science showed significant gains in their content knowledge.**

These teachers improved their pedagogy and teaching strategies, provided a positive classroom culture, and increased relevance and rigor in their classroom instruction. According to the Department of Education, this **lead to an average 6 percent gain in students' mathematics proficiency** from the previous year's assessment, and **an average of a 7 percent gain in science proficiency** from the previous assessment. This is twice the rate of the national average.

The urgent need to better fund the MSPs and to strengthen science and mathematics education was evident on April 29, 2008, when about 500 representatives of business, government, and academia met in Washington, D.C. at the National Academies of Science to review the efforts taken to achieve the goals laid out in *Rising above the Gathering Storm*. As you will recall the report recommended 20 specific actions in four broad areas the nation should take to improve our competitiveness. Vastly improving K-12 science and mathematics education was the number one action item identified in the report.

During the April 29 convocation many speakers pointed to the critical and fundamental need to improve K-12 science and math education. This quote from Norm Augustine, who chaired the committee that wrote the report, particularly stands out: *"A number of significant events have taken place since the Gathering Storm report was released; unfortunately most of those positive events have occurred in other countries. Governments around the world are boosting their support of science and engineering research, invigorating precollege science and math education, and investing in institutions of higher education. Meanwhile, the United States has made little progress in strengthening its education, research, and innovation systems."*

Research suggests that stronger teacher content knowledge and teaching skills in mathematics and science leads to improvements in students' achievement in these areas. Increased funding for



the Math and Science Partnerships will enable more states, schools, and higher education partnerships to invest in critically-needed teacher professional development in the sciences and mathematics. It will allow partners to scale-up current programs and to develop new programs for more teachers. Last week President Obama announced that his administration considered it a national imperative to dramatically improve student achievement in science and math and called on the nation and state governors to improve the quality of science and math teachers. We urge you to honor the Presidents request by fully funding Title II B, the Math and Science Partnerships, at the authorized level of \$450 million for FY2010.

TESTIMONY TO  
HOUSE SUBCOMMITTEE ON LABOR, HEALTH & HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES

SUBMITTED BY

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REGARDING

FISCAL YEAR 2010 FUNDING FOR THE  
DEPARTMENT OF HEALTH AND HUMAN SERVICES

April 30, 2009

**SUMMARY OF FY 2010 RECOMMENDATIONS**

- Provide \$5 million in funding for sleep activities within the Community Health Promotion account within the Chronic Disease Program at the Centers for Disease Control and Prevention (CDC). Expanded funding for sleep and sleep disorder-related activities would allow the CDC to create targeted public educational initiatives for schools and workplaces and training materials for current and future health professionals; build and test public health interventions; expand surveillance and epidemiological activities; and create fellowship and research opportunities.
- Encourage the National Institutes of Health to conduct multi-center clinical trials to evaluate whether healthcare costs and the incidence of stroke, cardiovascular disease and diabetes can be reduced by treating sleep disorders such as obstructive sleep apnea as part of usual care practices.

Mr. Chairman and members of the Subcommittee, thank you for allowing me to submit testimony on behalf of the National Sleep Foundation (NSF). I am Dr. Frankie Roman, Chair of the NSF's Government Affairs Committee and a sleep specialist at Ohio Sleep Disorder Centers, in Akron, Ohio. NSF is an independent, non-profit organization that is dedicated to improving public health and safety by achieving understanding of sleep and sleep disorders, and by supporting sleep-related education, research and advocacy. We work with sleep medicine and other health care professionals, researchers, patients and drowsy driving advocates throughout the country as well as collaborate with many government, public and professional organizations with the goal of preventing health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. It is estimated that sleep-related problems affect 50 to 70 million Americans of all ages and socioeconomic classes. Sleep disorders are common in both men and women; however, important disparities in prevalence and severity of certain sleep disorders have been identified in minorities and underserved populations. Despite the high prevalence of sleep disorders, the overwhelming majority of sufferers remain undiagnosed and untreated, creating unnecessary public health and safety problems, as well as increased health care expenses. Annual surveys conducted by NSF show that more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent have ever initiated such a discussion.

Additionally, Americans are chronically sleep deprived as a result of demanding lifestyles and a lack of education about the impact of sleep loss. Sleepiness affects vigilance, reaction times, learning abilities, alertness, mood, hand-eye coordination, and the accuracy of short-term memory. Sleepiness has been identified as the cause of a growing number of on-the-job accidents, automobile crashes and multi-modal transportation tragedies.

According to the National Highway Traffic Safety Administration's *2002 National Survey of Distracted and Drowsy Driving Attitudes and Behaviors*, an estimated 1.35 million drivers have been involved in a drowsy driving crash in the previous five years. According to NSF's 2009 *Sleep in America* poll, 54% of people report that they have driven drowsy at least once in the past year, with 28% reporting that they do so at least once a month or more! A large number of academic studies and government reports have linked lost productivity, poor school performance, and major public health problems to chronic sleep loss and sleep disorders.

The 2006 Institute of Medicine (IOM) report, *Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem*, found the cumulative effects of sleep loss and sleep disorders represent an under-recognized public health problem and have been associated with a wide range of negative health consequences, including hypertension, diabetes, depression, heart attack, stroke, and at-risk behaviors such as alcohol and drug abuse – all of which represent long-term targets of the Department of Health and Human Services (HHS) and other public health agencies. Moreover, the personal and national economic impact is staggering. The IOM estimates that the direct and indirect costs associated with sleep disorders and sleep deprivation total hundreds of billions of dollars annually.

Sleep science and federal reports have clearly demonstrated the importance of sleep to health, safety, productivity and well-being, yet other studies continue to show that millions of Americans are at risk for serious health and safety consequences of untreated sleep disorders and inadequate sleep, primarily due to a lack of awareness, community interventions, and screening procedures. Unfortunately, despite recommendations in numerous federal reports, there is a lack of epidemiological data, large clinical trials and no on-going national educational programs regarding sleep issues aimed at the general public, health care professionals, underserved communities or major at-risk groups.

NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. Sleep must be elevated to the top of the national health agenda in order to adequately address other national public health problems mentioned above. We need your help to make this happen.

First, one of the most devastating sleep disorders is obstructive sleep apnea (OSA), a sleep-related breathing disorder which affects at least 5% of adult Americans and is closely related to some of America's most pressing health problems, such as obesity, hypertension, heart failure, and diabetes. NSF and its partners, including the National Center on Sleep Disorders Research at the National Institutes of Health, have been working diligently to create better patient and primary care physician awareness of sleep apnea. However, despite considerable progress, sleep apnea remains woefully under-diagnosed and undertreated primarily due to a lack of understanding in the primary care community, good epidemiological data, and randomized evidence regarding long-term treatment. Therefore, we recommend that the National Institutes of Health be encouraged to conduct multi-center clinical trials to evaluate whether treatment of OSA can reduce healthcare costs and the incidence of stroke, cardiovascular disease and diabetes.

Secondly, our biggest challenge is bridging the gap between the outstanding scientific advances we have seen in recent years and the level of knowledge about sleep held by health care practitioners, educators, employers, and the general public. Because resources are limited and the challenges great, we think creative and new partnerships are needed to fully develop sleep awareness, education and clinical training initiatives. Consequently, the NSF has spearheaded important initiatives to raise awareness of the importance of sleep to the health, safety and well-being of the nation. One of our most important partnerships in these efforts is with the Centers for Disease Control and Prevention.

For the last five years, Congress has recommended that the CDC support activities related to sleep and sleep disorders. As a result, CDC's National Center for Chronic Disease Prevention and Health Promotion has been collaborating with NSF and more than twenty voluntary organizations and federal agencies to form the National Sleep Awareness Roundtable (NSART), which was officially launched in March of 2007. Congress also provided specific funding for these efforts for the past two years.

In FY 2008, Congress provided \$818,000 for activities related to sleep and sleep disorders, including CDC's participation in NSART and incorporating sleep-related questions into established CDC surveillance systems. With this funding, CDC included one core sleep question

in its national data collection efforts in 2008 and has provided grants to 8 states to include an optional sleep module in their data collection efforts through the Behavioral Risk Factor Surveillance System (BRFSS), which will occur in the summer of 2009. CDC also included one question in the Youth Risk Behavior Surveillance System (YRBSS) and found that only one-third high-school student had 8 or more hours of sleep on an average school night, far below the 9.25 hours recommended by physicians for that age group. This new data will provide important information on the prevalence of sleep disorders and enable researchers to better address the complex interrelationship between sleep loss and comorbid conditions such as obesity, diabetes, depression, hypertension, and drug and alcohol abuse.

Additionally, CDC and NSART participated in NSF's national public awareness initiatives including National Sleep Awareness Week and Drowsy Driving Prevention Week. CDC also launched its own Sleep and Sleep Disorders Web Site, created a fellowship position to analyze sleep and chronic disease data, held a Sleep and Public Health Workshop at the CDC campus, and released a number of multi-media health marketing materials to promote better sleep.

In FY 2009, Congress provided \$900,000 to the CDC for sleep activities. CDC plans to expand the number of states it is able to fund for BRFSS data collection and provide support for national public and professional awareness initiatives as well as activities of the National Sleep Awareness Roundtable.

NSF and NSART have actively been involved in conducting outreach to public health officials and are currently working to develop a National Action Plan. This document will address what is required to organize a successful collaboration to implement effective public and professional awareness and education initiatives primarily aimed at the diagnosis and treatment of obstructive sleep apnea and the promotion of sleep as a healthy behavior. NSART is seeking to expand its membership by reaching out to new organizations and state and federal agencies that are interested in raising awareness of sleep issues and implementing NSART initiatives.

Although the CDC has taken initial steps to begin to consider how sleep affects public health issues, the agency needs additional resources to take appropriate actions, as recommended by the IOM and other governmental reports.

Expanded funding for sleep and sleep disorder-related activities would allow the CDC to create much needed educational programs for schools and occupational settings and training materials for current and future health professionals; build and test public health interventions; expand surveillance and epidemiological activities; and create further fellowships and research opportunities. The following are detailed scenarios for various funding levels.

- **\$2 million:**

- **Expand Surveillance on BRFSS.** CDC could double the number of grants it provides to states to use the optional sleep module and include more core questions in the nationwide data collection through the Behavioral Risk Factor Surveillance System. CDC would also expand its participation in and funding of national public and professional initiatives as well as the goals and activities of the National Sleep Awareness Roundtable.

- **\$5 million** – All activities detailed in the \$2 million scenario, plus:
  - **Public Education.** CDC could support the development of a national sleep health communications campaign that use targeted approaches for delivering sleep-related messages, especially in public schools and workplaces. Currently, no such programs exist.
  - **Training Materials.** Tools and programs could be developed for current and future health professionals, including school nurses, to promote sleep as a healthy behavior and increase the diagnosis and treatment of sleep disorders. Today, most health care professionals receive no such training, which increases the nation's health burden.

NSF and members of the National Sleep Awareness Roundtable believe that an ongoing partnership with CDC is critical to address the enormous public health impact of sleep and sleep disorders. We hope that the Committee will provide funding of \$5,000,000 to the CDC to execute programs as outlined here.

Thank you again for the opportunity to present you with this testimony.

**National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT)**  
**U.S. Department of Education**  
**Submitted by: Dr. T. Alan Hurwitz**  
**President, NTID and Vice President and Dean, RIT**  
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Mr. Chairman and Members of the Committee:

I am pleased to present the FY 2010 budget request for NTID, one of eight colleges of RIT, in Rochester NY. Created by Congress, we provide university technical education, serving a total of 1,450 students, including 1,284 deaf and hard-of-hearing students from across the nation and 166 hearing students. NTID students live, study and socialize with more than 15,000 hearing students on the RIT campus.

NTID has fulfilled our mission with distinction for 41 years.

**BUDGET REQUEST:** This request details the importance of obtaining our full FY 2010 request of **\$71,352,000**. We ask for **\$65,952,000** for continuing operations and **\$5,400,000** for construction to replace aging mechanical systems as detailed below. The NTID and President's requests are:

	<b>Operations</b>	<b>Construction</b>	<b>Total</b>
<b>NTID Request</b>	\$65,952,000	\$5,400,000	\$71,352,000
<b>President's Request*</b>	\$63,037,000	\$5,400,000	\$68,437,000
<b>Difference</b>	<b>\$2,915,000</b>	<b>\$0</b>	<b>\$2,915,000</b>

\*NOTE: These numbers are our understanding of what the President will submit to Congress.

We respectfully request your support of our full appropriation request. We do not request new operations funding for additional academic programs or headcount; instead, we commit to fund increases, if any, through reallocating resources. This commitment continues our history of funding changes through internal reallocation. From FY 2003 through FY 2007 we documented \$6,200,000 in budget reductions, including the elimination of 49 headcounts, and increasing our revenues. These difficult savings allowed us to improve our programs and services while limiting our request for federal support. As one example, we dramatically increased the number of captionists employed to deliver in-

classroom speech-to-text real-time access services to students, without additional funding.

We are proud of those cost savings and reallocations accomplishments.

Our FY 2010 operations request represents costs driven by personnel and health benefits, as well as payment for services provided by RIT that are subject to the same inflationary pressures. The significant enrollment increases detailed below add proportionally to anticipated costs. We do not ask for funds to address program modifications; we will reallocate to meet those needs.

**ENROLLMENT:** As we prepare to enter FY 2010, we do so having attracted, in FY 2009, the largest enrollment in our 41-year history. Truly a national program, NTID enrolls students from all 50 states. Current enrollment of 1,450; in the last two years our enrollment has increased by 200 students, an increase of 16%. For FY 2010, NTID anticipates maintaining or slightly increasing enrollment. Our five-year enrollment history follows.

NTID Enrollments: Five-Year History								
Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2005	1,055	42	49	1,146	100	35	135	1,281
2006	1,013	53	38	1,104	116	36	152	1,256
2007	1,017	47	31	1,095	130	25	155	1,250
2008	1,103	51	31	1,185	130	28	158	1,353
2009	1,212	48	24	1,284	135	31	166	1,450

**STUDENT ACCOMPLISHMENTS:** For our graduates, 95% have been placed in jobs commensurate with the level of their education (using the Bureau of Labor Statistics methodology). Of our FY 2007 graduates (the most recent class for which numbers are available), 63% were employed in business and industry, 29% in education/non-profits, and 8% in government.

Graduation from NTID has a significant, positive effect on earnings over a lifetime, and results in a noteworthy reduction in dependence on welfare programs. In FY 2007, NTID, the Social Security Administration, and Cornell University examined approximately 13,000 deaf and hard-of-hearing



individuals who applied and attended NTID over our entire history. We learned NTID graduation has significant economic benefits. By age 50, deaf and hard-of-hearing baccalaureate graduates earned on average \$6,021 more per year than those with associate degrees, who in turn earned \$3,996 more per year on average than those who withdraw. Students who withdraw earned \$4,329 more than those who were not admitted. Students who withdrew experienced twice the rate of unemployment as graduates.

The same studies showed 78% of these individuals were receiving Supplemental Security Income (SSI) benefits at age 19, but when they were 50 years old, only 1% of graduates drew these benefits, while on average 19% of individuals who withdrew or were rejected for admission continued to participate in the SSI program. Graduates also accessed Social Security Disability Insurance (SSDI), an unemployment benefit, at far lesser rates than students who withdrew; by age 50, 34% of non-graduates were receiving SSDI, while only 22% of baccalaureate graduates were receiving them and only 27% of associate graduates were receiving them. Considering the reduced dependency on these federal income support programs, the federal investment in NTID returns significant societal dividends.

NTID clearly makes a significant, positive difference in earnings, and in lives.

**NEW “MILITARY VETERANS WITH HEARING LOSS” PROGRAM:** In FY 2010, NTID will establish the “Military Veterans with Hearing Loss” program to enroll veterans who have suffered significant hearing loss as a result of their military service. Recently returned veterans with hearing loss can earn bachelor or graduate-level degrees at RIT with access services – such as real-time captioning and notetaking in the classroom – from NTID. Our faculty and staff are experienced in helping those with sudden hearing loss, and we provide comprehensive services for those with hearing aids or cochlear implants.

The access services provided at NTID are unparalleled. More than 50 classroom captionists provide real-time captioning to students. More than 120 sign language interpreters support students who benefit from interpreting.

As many as 10 veterans could be admitted each year, growing to 50 veterans over time. (RIT also recently announced it will become a “Yellow Ribbon” institution.)

**CONSTRUCTION:** For the past three years, NTID has informed Congress of on-going planning to replace the deteriorating 25 boilers and 23 chillers in individual buildings throughout the RIT campus. Existing heating, ventilation and air conditioning systems remain from the original campus construction over 40 years ago. Although prudent in providing on-going maintenance, RIT/NTID reached a point where normal maintenance was no longer feasible and the decision was reached to replace the existing system with five new boilers and seven new chillers

All of the buildings and spaces devoted to NTID programs across the RIT campus are connected to this system. An analysis determined the square footage used by NTID in each building serviced by the new system, and the resulting proportion of the total expenses was allocated to NTID. That analysis showed that NTID buildings and other spaces utilized 15% of the total square footage. With a total project cost of \$36,000,000, NTID is responsible for \$5,400,000 (15%) of the total cost, which we request for FY 2010.

In addition to discussions with Congress, this request has been discussed repeatedly over several years with the U.S. Department of Education (ED); presentations and facilities tours were provided during oversight visits to NTID. We understand that the President supports this request, and we ask that Congress also support this construction cost.

**NTID BACKGROUND:**

*Academic Programs.* NTID offers high quality, career-focused, associate degree programs preparing students for specific well-paying technical careers. A cooperative education component ties closely to high demand employment opportunities. Expanding transfer associate degree programs better serve the higher achieving segment of our student population who seek bachelors and masters degrees in an increasingly demanding marketplace. These transfer programs provide seamless transition to

baccalaureate studies in other colleges of NTID where we support students in baccalaureate programs with access services and tutoring. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students gain admission to and graduate from the other colleges of RIT at rates that are better than their hearing peers.

*Research.* Our research program is guided and organized according to these general research areas: language and literacy, teaching and learning, socio-cultural influences, career development, technology integration, and institutional research. All benefit the deaf and hard-of-hearing population.

*Outreach.* Extended outreach activities to junior/senior high school students, expand their horizons regarding a college education. We also serve other universities and post-college adults.

*Student Life.* Our activities foster student leadership and community service, and provide opportunities to explore other educational interests.

**SUMMARY:** It is extremely important that our funding be provided at the full level requested as we continue our mission to prepare deaf and hard-of-hearing people to enter the workplace and society.

Our alumni have demonstrated that they can achieve independence, contribute to society, earn a living, and live a satisfying life as a result of NTID. Research shows that NTID graduates over their lifetimes are employed at a much higher rates, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in federal welfare programs than those who withdraw or who apply but do not attend NTID.

We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of federal funds and outstanding educational record of service with deaf and hard-of-hearing people, remains deserving of your support and confidence.

**Kevin Coyle**  
**Vice President for Education and Training**  
**National Wildlife Federation**  
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**Testimony on the University Sustainability Program (USP), Energy Conservation Corps,  
Green Jobs Education and Training and Related Programs**

**For the**  
**Subcommittee on Labor, Health and Human Service, Education and Related Agencies**  
**Committee on Appropriations**  
**U.S. House of Representatives**

Mr. Chairman, Members of the Subcommittee, on behalf of the National Wildlife Federation (NWF), our nation's largest conservation advocacy and education organization, and our more than four million members and supporters, I thank you for the opportunity to provide funding recommendations for the Department of Education, Department of Labor (DOL), and the Corporation for National and Community Service (CNCS).

We believe that the overall federal investment in environmental education and sustainability education programs nationwide – pennies per capita – is woefully inadequate. While NWF supports numerous programs under the jurisdiction of this Subcommittee, the purpose of this testimony is to recommend levels of funding for specific sustainability education, green jobs education and training, and national service programs that we believe are vital to NWF's mission to inspire Americans to protect wildlife for our children's future. The National Wildlife Federation also supports climate change education and environmental education programs across the federal agencies at the U.S. Forest Service, Environmental Protection Agency, National Science Foundation, National Space and Atmospheric Administration, National Oceanic and Atmospheric Administration, and U.S. Department of Interior.

**Summary of Recommendations:**

<b>Agency</b>	<b>Program</b>	<b>FY 2010 Recommendation</b>	<b>FY 2009 Level</b>
<b>Education</b>	University Sustainability Program	\$50 million	Not Authorized in FY09
<b>Education</b>	Healthy High Performance Schools	\$25 million	\$0 million
<b>Labor</b>	Green Jobs Act	\$125 million	Funded at \$500 million total in ARRA
<b>Labor</b>	Community Based Jobs Training Grants	\$250 million – green priority	\$125 million
<b>CNCS</b>	Clean Energy Service Corps	\$100 million	Not Authorized in FY09

### **The Need for Environmental Education and Sustainability Education**

As our nation moves towards a clean energy economy and creates new “green jobs,” we must ensure that our education and training infrastructure keeps pace. Congress and President Obama have stated their desire to cap global warming pollution this year, a priority that the National Wildlife Federation strongly supports. To be successful as a nation under a new cap and trade system, we must have an environmentally literate citizenry that has the knowledge and skills to find new and innovative solutions to protect our planet. While public awareness and concern about global warming continues to rise, the vast majority of the public does not understand how climate change works, how it impacts their lives and careers, and how their decisions and actions contribute to it. Consider the following examples:

- Survey research shows that most Americans do not know what the carbon cycle is or understand what actually causes global warming. They do not know how most electricity is generated or the importance of healthy forests and oceans in generating oxygen and absorbing carbon dioxide.
- Less than half of the population recognizes that the cars and appliances they use contribute to global warming, and eight out of 10 parents admit that they know “little” to “nothing” about the specific causes of climate change.
- The average high school student fails a quiz on the causes and consequences of climate change (nearly 82 percent of participants affirmed, incorrectly, that “scientists believe radiation from nuclear power plants cause global temperatures to rise.”).
- In addition, most students don't see themselves at risk: Only 28 percent believe it's very likely that climate change will affect them personally in their lifetimes.

**Educating Americans about climate change is a huge opportunity** for our nation to prepare today's leaders, and the leaders of tomorrow, to implement the solutions created by a cap and trade system. Unfortunately, some still mistakenly see environmental protection programs as a costly burden on prosperity. In fact, the challenge posed is an entrepreneur's dream. Addressing global warming will generate millions of good new jobs and put the U.S. at the exciting forefront of a new clean energy economy. The successful transition to this new green economy hinges on education and training. This testimony focuses on key programs that educate and train Americans at institutions of higher education, through conservation corps programs that educate and train at-risk youth for careers in clean energy, and through green workforce education and training programs through the Department of Labor.

#### **Department of Education:**

##### University Sustainability Program

**The National Wildlife Federation supports funding the newly authorized University Sustainability Program (USP) at \$50 million in FY 2010.** Interest in sustainability is exploding on college campuses across the nation, and institutions are making remarkable changes to try to reduce campus carbon footprints and energy use. However, despite increasing interest and demand from students, sustainability education programs on college campuses are on the decline according to a comprehensive study released in August 2008 by the National Wildlife Federation and Princeton Survey Research Associates International, called the

“Campus Environment 2008: A National Report Card on Sustainability in Higher Education.” Environmental curriculum requirements are slipping and today’s students may be less environmentally literate when they graduate than their predecessors.

Congress recently authorized a new University Sustainability Program (USP) at the Department of Education as Part U of the recently enacted Higher Education Opportunity Act of 2008 (H.R. 4137). This program has the potential for high impact, high visibility, broad support within higher education, and is responsive to an important national trend in higher education. Sustainability on college campuses is critical, from education in the classroom to facility operations. Higher education produces almost all of the nation’s leaders in all sectors and endeavors, and many college campuses are virtually small cities in their size, environmental impact, and financial influence. Campuses use vast amounts of energy to heat, cool, and light their facilities. In all, the nation’s 4,100 campuses educate or employ around 20 million individuals and generate over three percent of the nation’s GDP. The economic clout of these schools is further multiplied by the hundreds of thousands of business suppliers, property owners, and other commercial and nonprofit entities involved with higher education. Funding for the newly authorized USP is critical to help provide difficult-to-get seed funding to launch sustainability education programs and to help support mainstream higher education associations in including sustainability in their work with their member institutions.

#### Healthy High Performance Schools Program

**The National Wildlife Federation supports funding the Healthy High Performance Schools Program at \$25 million in FY 2010.** The Healthy High Performance Schools Program seeks to facilitate the design, construction and operation of high performance schools: environments that are not only energy and resource efficient, but also healthy, comfortable, well lit, and containing the amenities for a quality education. This grant program is critical at a time when energy costs for America’s elementary and secondary schools are skyrocketing. The No Child Left Behind Act (PL 107-110, Title 5, Part D, Subtitle 18) authorized grants to state education agencies to advance the development of “healthy, high performance” school buildings. States may use the funds to provide information, technical assistance, monitor, evaluate, and provide funding to local education agencies for healthy, high performance school buildings. In turn, local agencies may use the funding to obtain technical assistance, develop plans that address reducing energy and meet health and safety codes, and conduct energy audits. Funds may not be used for construction, maintenance, repair or renovation of buildings. This program has yet to be funded by Congress. While it would seem to be a given that we are providing our children with a healthy learning environment, many of the nation’s 150,000 public school buildings fall far short of this standard. Research clearly shows that improving specific factors such as school indoor environmental quality improves attendance, academic performance, and productivity.

The National Wildlife Federation also supports a priority for funding **green** Career and Technical Education programs and initiatives at the Department of Education.

While not yet authorized, the National Wildlife Federation strongly supports authorization of and full funding at \$100 million per year for the **No Child Left Inside (NCLI) Act of 2009**, which has the support of more than 1,300 national, state and local organizations representing more than 45 million Americans. The central new policy in this legislation is the incentive for states to

create or update a State Environmental Literacy Plan. Environmental Literacy Plans can be developed to meet the needs of each state and systemically advance environmental education through the K-12 education system. These state plans support teacher training and professional development and support capacity building for environmental education. The House passed a modified version of the bill in the 110<sup>th</sup> Congress by a bipartisan vote of 293-109.

**Department of Labor:**

The National Wildlife Federation supports a priority for green jobs education and training at the Department of Labor through the Workforce Investment Act Adult and Youth funding streams, the Energy Efficiency and Renewable Energy Worker Training Program, and the Community Based Job Training program.

Energy Efficiency and Renewable Energy Worker Training Program

**The National Wildlife Federation supports funding the Energy Efficiency and Renewable Energy Worker Training Program at \$125 million in FY 2010.** NWF greatly appreciates this Subcommittee's first-time investment in Green Jobs Education and Training in the recent American Recovery and Reinvestment Act. This unprecedented investment will help jumpstart the education and training needed to prepare Americans for the clean energy economy. We hope that the Committee will fund The Green Jobs Act (GJA), Title X of the Energy Independence and Security Act, which authorizes \$125 million per year in grants for an Energy Efficiency and Renewable Energy Worker Training Program. NWF is seeking \$125 million in this FY 2010 bill, recognizing that the Subcommittee will assess how the investment through ARRA is spent before making new funding available. NWF believes it is important to make annual investments in this program through the regular appropriations process, in addition to necessary infusions of funding through stimulus and supplemental bills. This program identifies needed skills, develops training programs, and trains workers for jobs in a range of green industries, but has a special focus on creating "green pathways out of poverty." The program is administered by the Department of Labor in consultation with the Department of Energy. The Act responds to already existing skill shortages. The National Renewable Energy Lab has identified a shortage of skills and training as a leading barrier to renewable energy and energy efficiency growth. This labor shortage is only likely to get more severe as baby-boomers skilled in current energy technologies retire; in the power sector, for example, nearly one-quarter of the current workforce will be eligible for retirement in the next five to seven years.

Community Based Job Training Grants Program

**The National Wildlife Federation supports funding the Community-Based Job Training Grants Program at \$250 million in FY 2010.** NWF believes that community colleges are critical partners in training and educating the next generation of Americans for green jobs. NWF supports a priority within this program for green jobs education and training grants. The Community-Based Job Training Grants program supports partnerships of community colleges, business, and workforce investment boards seeking to train workers for high-demand occupations. These competitive grants help ensure that efforts funded through the program are well coordinated with other local and regional workforce development efforts. Community-Based Job Training Grants support workforce training for high-growth industries through the nation's community and technical colleges. Their primary purpose is to build community

colleges' capacity to equip workers with the skills required to succeed in local industries. Training will prepare workers for jobs that are expected to experience high growth and industries where demand for qualified workers is outstripping supply, such as green jobs and health care.

**Corporation for National and Community Service:**

Clean Energy Service Corps

**The National Wildlife Federation supports funding the Clean Energy Service Corps at \$100 million in FY 2010.** The Clean Energy Service Corps, building on the legacy of the depression-era Civilian Conservation Corps and modeled after today's Service and Conservation Corps, will address the nation's energy and environmental needs while providing work and service opportunities, especially for disadvantaged youth ages 16-25. In a manner similar to the Civilian Conservation Corps of the 1930s, disconnected young people may be mobilized through this program to retrofit, weatherize, and otherwise improve the energy efficiency of residential and public facilities that account for more than 40 percent of carbon emissions. Specific projects that are authorized include weatherizing and retrofitting housing units for low-income households, cleaning and improving rivers, and working with schools and youth programs to educate students and youth about ways to reduce home energy use and improve the environment.

**Conclusion**

Providing federal support for environmental education, sustainability education, green jobs education and training and green national service programs is critical for securing our new clean energy future and preparing the next generation for the challenges and opportunities ahead. Thank you again for providing the National Wildlife Federation with the opportunity to provide testimony.





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**STATEMENT OF  
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**ON BEHALF OF THE  
NEPHCURE FOUNDATION  
15 WATERLOO AVENUE, SUITE 200  
BERWYN, PA 19312**

**FISCAL YEAR 2010 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE  
AND KIDNEY DISEASES**

**SUBMITTED TO THE  
HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES**

**MAY 1, 2009**

**SUMMARY OF RECOMMENDATIONS FOR FY10:**

- 1) PROVIDE A 7.0% FUNDING INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK).**
- 2) SUPPORT DEVELOPMENT OF THE *NEPHROTIC SYNDROME RARE DISEASE CLINICAL RESEARCH NETWORK* AT THE OFFICE OF RARE DISEASES RESEARCH (ORD).**
- 3) SUPPORT DEVELOPMENT OF A PATIENT REGISTRY WITHIN THE NIDDK TO FACILITATE COLLABORATIVE RESEARCH EFFORTS.**
- 4) SUPPORT CONTINUED EXPANSION OF THE FSGS/NS RESEARCH PORTFOLIO AT NIDDK BY FUNDING MORE RESEARCH PROPOSALS GENERATED BY THE RECENT PROGRAM ANNOUNCEMENT *GRANTS FOR BASIC RESEARCH IN GLOMERULAR DISEASE (R01)* (PA-07-367).**

### One Family's Story

Chairman Obey and members of the Subcommittee thank you for the opportunity to provide written testimony today, I am Dee Ryan and my husband is Lieutenant Colonel John Kevin Ryan, an Iraq war veteran. I would like to tell you about my 6 year old daughter Jenna's nephrotic syndrome (NS), a medical problem caused by rare diseases of the kidney filter. When affected, these filters leak protein from the blood into the urine and often cause kidney failure requiring dialysis or kidney transplantation. We have been told by our physician that Jenna has one of two filter diseases called Minimal Change Disease (MCD) or Focal and Segmental Glomerulosclerosis (FSGS). According to a Harvard University report there are presently 73,000 people in the United States who have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are very poorly understood.

In October of 2007 my daughter began to experience general swelling of her body and intermittent abdominal pain, fatigue and general malaise. Jenna began to develop a cough and her stomach became dramatically distended. We rushed Jenna to the emergency room where her breathing became more and more labored and her pulse raced. She had symptoms of pulmonary edema, tachycardia, hypertension, and pneumonia. Her lab results showed a large amount of protein in the urine and a low concentration of the blood protein albumin, consistent with the diagnosis of FSGS. Jenna's condition did not begin to stabilize for several frightening days.

Following her release from the hospital we had to place Jenna on a strict diet which limited her consumption of sodium to no more than 1,000 mg per day. Additionally, Jenna was placed on a steroid regimen for the next three months. We were instructed to monitor her urine protein levels and to watch for swelling and signs of infection, in order to avoid common complications such as overwhelming infection or blood clots. Because of her disease and its treatment, which requires strong suppression of the immune system, Jenna did have a serious bacterial infection several months after she began treatment.

We are frightened by her doctor's warnings that NS and its treatment are associated with growth retardation and other medical complications including heart disease. As a result of NS, Jenna has developed hypercholesterolemia and we worry about the effects the steroids may have on her bones and development. This is a lot for a little girl in kindergarten to endure.

Jenna's prognosis is currently unknown because NS can reoccur. Even more concerning to us is that Jenna may eventually lose her kidneys entirely and need dialysis or a kidney transplant. While kidney transplantation might sound like a cure, in the case of FSGS, the disease commonly reappears after transplantation. And even with a transplant, end stage renal disease caused by FSGS dramatically shortens one's life span.

The NephCure Foundation has been very helpful to my family. They have provided us with educational information about NS, Minimal Change Disease, and FSGS and the organization works to provide grant funding to scientists for research into the cause and cure of NS.

Mr. Chairman, because the causes of Nephrotic Syndrome are poorly understood, and because we have a great deal to learn in order to be able to effectively treat NS, I am asking you to please significantly increase funding for the National Institutes of Health. Also, please support the establishment of a collaborative research network that would allow scientists to create a patient registry and biobank for NS/FSGS, and that would allow coordinated studies of these deadly diseases for the first time. Finally, please urge the National Institute of Diabetes and Digestive and Kidney Disease to continue to focus on FSGS/NS research in general, consistent with the recent program announcement entitled *Grants for Basic Research in Glomerular Disease (R01)* (PA-07-367).

Mr. Chairman, on behalf of the thousands of people suffering from NS and FSGS and the NephCure Foundation, thank you for this opportunity to submit this testimony to the Subcommittee and for your consideration of my request; Thank you.

#### More Research is Needed

We are no closer to finding the cause or the cure of FSGS. Scientists tell us that much more research needs to be done on the basic science behind the disease.

NephCure Foundation, the University of Michigan, and other important university research health centers have come together to support the establishment of the *Nephrotic Syndrome Rare Disease Clinical Research Network*. This network is a new collaboration between research institutions and the NephCure Foundation supporting research on NS and FSGS. This initiative has tremendous potential to make significant advancements in NS and FSGS research by pooling efforts and resources. The addition of federal resources to this important initiative is crucial to ensuring the best possible outcomes for the *Nephrotic Syndrome Rare Disease Clinical Research Network* occur.

NCF is also grateful to the NIDDK for issuing of a program announcement (PA) that serves to initiate grant proposals on glomerular disease. The PA, issued in March of 2006, is glomerular-disease specific. The announcement will utilize the R01 mechanism to award researchers funding.

**We ask the Committee to encourage the ORD to support the *Nephrotic Syndrome Rare Disease Clinical Research Network* to expand FSGS research. We also ask the NIDDK to continue to issue glomerular disease program announcements.**

#### Too Little Education About a Growing Problem

When glomerular disease strikes, the resulting NS causes a loss of protein in the urine and edema. The edema often manifests itself as puffy eyelids, a symptom that many parents and physicians mistake as allergies. With experts projecting a substantial increase in nephrotic syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

We also applaud the work of the NIDDK in establishing the National Kidney Disease Education Program (NKDEP), and we seek your support in urging the NIDDK to make sure that glomerular disease remains a focus of the NKDEP.

**We ask the Committee to encourage the NIDDK to have glomerular disease receive high visibility in its education and outreach efforts, and to continue these efforts in conjunction with the NephCure Foundation's work. These efforts should be targeted towards both physicians and patients.**

#### Glomerular Disease Strikes Minority Populations

Nephrologists tell us that glomerular disease strikes a disproportionate number of African-Americans. No one knows why this is, but some studies have suggested that a genetic sensitivity to sodium may be partly responsible. DNA studies of African Americans who suffer from FSGS may lead to insights that would benefit the thousands of African Americans who suffer from kidney disease.

I ask that the NIH pay special attention to why this disease affects African-Americans to such a large degree. The NephCure Foundation wishes to work with the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to encourage the creation of programs to study the high incidence of glomerular disease within the African American population.

There is also evidence to suggest that the incidence of glomerular disease is higher among Hispanic Americans than in the general population. An article in the February 2006 edition of the NIDDK publication *Recent Advances and Emerging Opportunities*, discussed the case of Frankie Cervantes, a six year old boy of Mexican and Panamanian descent. Frankie has FSGS received a transplanted kidney from his mother. We applaud the NIDDK for highlighting FSGS in their publication, and for translating the article about Frankie into both English and Spanish. Only through similar efforts at cross-cultural education can the African-American and Hispanic-American communities learn more about glomerular disease.

**We ask the Committee to join with us in urging the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to collaborate on research that studies the incidence and cause of this disease among minority populations. We also ask that the NIDDK and the NCMHD undertake culturally appropriate efforts aimed at educating minority populations about glomerular disease.**

#### Patient Registry and Biobank

Experts currently believe glomerular disease is increasing in frequency and it is often misdiagnosed or undetected and, as a result, is often unreported. Since many cases of glomerular disease are unreported, it is difficult to ascertain different aspects of the disease and to form more comprehensive data sets on the patient population. While databases and registries have helped defeat other diseases, one does not exist for FSGS.

The development of a biobank would be beneficial in understanding the genetic components of glomerular disease and their corresponding interactions with environmental factors.

**We ask the Committee to support the funding of the first-ever national database/registry for FSGS within NIDDK. Experts say that the incidence of FSGS is increasing and that the disease is often misdiagnosed, undetected or unrecorded. We also ask the Subcommittee support the development of a biobank as a further means of understanding the causes of FSGS, both genetic and environmental.**

**Testimony Submitted to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education**

**Karen Peluso, Executive Director, Neurofibromatosis, Inc., Northeast  
(781) 272-9936, [kpeluso@nfincne.org](mailto:kpeluso@nfincne.org)**

**April 15, 2009**

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, learning disabilities, heart disease, memory loss, brain tumors, and other disorders affecting up to 175 million Americans in this generation alone. Thanks in large measure to this Subcommittee's strong and enduring support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

On behalf of Neurofibromatosis, Inc., Northeast, a participant in a national coalition of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases linked to NF.

**What is Neurofibromatosis (NF)?**

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and/or death. NF can also cause other abnormalities such as unsightly benign tumors across the entire body and bone deformities. In addition, approximately one-half of children with NF suffer from learning disabilities. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

NF is not rare. It is three times more common than Multiple Sclerosis (MS) and Cystic Fibrosis combined, but is not widely known because it has been poorly diagnosed for many years. Approximately 100,000 Americans have NF, and it appears in approximately one in every 3,000 births. It strikes worldwide, without regard to gender, race or ethnicity. Approximately 50 percent of new NF cases result from a spontaneous mutation in an individual's genes, and 50 percent are inherited. There are two types of NF: NF1, which is more common, and NF2, which primarily involves tumors causing deafness and balance problems. In addition, advances in NF research stand to benefit over 175 million Americans in this generation alone because NF, the most common neurological disorder caused by a single gene, is directly linked to many of the most common diseases affecting the general population.

If a child was diagnosed with NF it would mean tumors could grow anytime, anywhere on his/her nervous system, from the day he/she was born until the day he/she died with no way to predict when or how severely the tumors would affect his/her body - and no viable way to treat the disease outside of surgery - which often results in more tumors that grow twice as fast. That same child would then have a 50% chance to pass the gene to his/her children. That's an overwhelming diagnosis and it bears repeating: NF is one of the most common genetic disorders

in our country and has no cure and no viable treatment. But that is changing. The immediate future holds real promise.

#### **Link to Other Illnesses**

Researchers have determined that NF is closely linked to cancer, heart disease, learning disabilities, memory loss, brain tumors, and other disorders including deafness, blindness and orthopedic disorders.

*Cancer* – NF is closely linked to many of the most common forms of human cancer, affecting approximately 65 million Americans, because of its tumor suppressor function. Research has demonstrated that NF's tumor suppressor protein, neurofibromin, inhibits RAS, one of the major malignancy causing growth proteins involved in 30 percent of all cancer. Accordingly, advances in NF research may well lead to treatments and cures not only for NF patients but for all those who suffer from cancer and tumor-related disorders. Similar studies have also linked epidermal growth factor receptor (EGF-R) to malignant peripheral nerve sheath tumors (MPNSTs), a form of cancer which disproportionately strikes NF patients.

*Heart disease* – Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same *ras* involved in cancer also causes heart valves to close. Neurofibromin, the protein produced by a normal NF1 gene, suppresses *ras*, thus opening up the heart valve. Promising new research has also connected NF1 to cells lining the blood vessels of the heart, with implications for other vascular disorders including hypertension, which affects approximately 50 million Americans. Researchers believe that further understanding of how an NF1 deficiency leads to heart disease may help to unravel molecular pathways affected in genetic and environmental causes of heart disease.

*Learning disabilities* – Learning disabilities are the most common neurological complication in children with NF1. Research aimed at rescuing learning deficits in children with NF could open the door to treatments affecting 35 million Americans and 5 percent of the world's population who also suffer from learning disabilities. Leading researchers have already rescued learning deficits in both mice and fruit flies with NF1 with a number of drugs, and clinical trials have now been approved by the FDA. This NF research could potentially save federal, state, and local governments, as well as school districts billions of dollars annually in special education costs resulting from a treatment for learning disabilities. It also holds enormous implications for understanding and treating associated social and behavioral problems in children who suffer from learning disabilities.

*Memory Loss* – Researchers have also determined that NF is closely linked to memory loss and are now investigating conducting clinical trials with drugs that may not only cure NF's cognitive disorders but also result in treating memory loss as well with enormous implications for patients who suffer from Alzheimer's disease and other dementias.

*Deafness* – NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors, including schwannomas and meningiomas, as well as being a major cause of balance problems.

### **Scientific Advances**

Thanks in large measure to this Subcommittee's support; scientists have made enormous progress since the discovery of the NF1 gene in 1990. Major advances in just the past few years have ushered in an exciting era of clinical and translational research in NF with broad implications for the general population.

These recent advances have included:

- Phase II and Phase III clinical trials involving new drug therapies for both cancer and cognitive disorders;
- Creation of a National Clinical and Pre-Clinical Trials Infrastructure and NF Centers;
- Successfully eliminating tumors in NF1 and NF2 mice with the same drug;
- Developing advanced mouse models showing human symptoms;
- Rescuing learning deficits and eliminating tumors in mice with the same drug;
- Determining the biochemical, molecular function of the NF genes and gene products;
- Connecting NF to more and more diseases because of NF's impact on many body functions.

### **Future Directions**

NF research has now advanced to the translational and clinical stages which hold incredible promise for NF patients, as well as for patients who suffer from many of the diseases linked to NF. This research is costly and will require an increased commitment on the federal level. Specifically, future investment in the following areas would continue to advance research on NF:

- Clinical trials;
- Funding of clinical trials network to connect patients with experimental therapies;
- DNA Analysis of NF tissues;
- Development of NF Centers, tissue banks, and patient registries;
- Development of new drug and genetic therapies;
- Further development of advanced animal models;
- Expansion of biochemical research on the functions of the NF gene and discovery of new targets for drug therapy; and
- Natural history studies and identification of modifier genes – studies are already underway to provide a baseline for testing potential therapies and differentiate among different phenotypes of NF.

### **Congressional support for NF research**

The enormous promise of NF research – and its potential to benefit over 175 million Americans in this generation alone – has gained increased recognition from Congress and the NIH. This is evidenced by the fact that ten institutes at NIH are currently supporting NF research (NCI, NHLBI, NINDS, NIDCD, NHGRI, NCRR, NMH, NIGMS, NIAMS, and NIA), and NIH's total research portfolio has increased from \$3 million in FY1990 to \$14 million in FY 2008. However, we are concerned that the NF research portfolio at NIH has declined by several million dollars in recent years (FY05 \$17 million, FY06 \$16 million, FY07 \$13 million), despite appropriations report language recommending a greater investment. Given the potential offered

by NF research for progress against a range of diseases, we are hopeful that NIH will substantially increase NF research funding.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued.

Thank you again for the opportunity to tell you of the progress and potential of NF research.



**Oncology Nursing Society**  
**Written Testimony to the House Labor-Health and Human Services**  
**Appropriations Subcommittee**  
**Regarding Fiscal Year 2010 Nursing and Cancer Related Funding**  
**Submitted by: Paula Rieger, CEO Oncology Nursing Society**  
**(412) 859-6314 and [prieger@ons.org](mailto:prieger@ons.org)**  
**May 1, 2009**

**Overview**

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2010 funding for cancer and nursing related programs. ONS, the largest professional oncology group in the United States, composed of more than 37,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

In 2009, an estimated 1.44 million Americans will be diagnosed with cancer, and more than 565,650 will lose their battle with this terrible disease; at the same time the national nursing shortage is expected to worsen. Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older.<sup>1</sup> Despite these grim statistics, significant gains in the war against cancer have been made through our nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless, unless we can deliver them to all Americans in need. Moreover, a recent survey of ONS members found that the nursing shortage is having an adverse impact in oncology physician offices and hospital outpatient departments. Some respondents indicated that when a nurse leaves their practice, they are unable to hire a replacement due to the shortage – leaving them short-staffed and posing scheduling challenges for the practice and the patients. These vacancies in all care settings create significant barriers to ensuring access to quality care.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates ongoing and significant federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. ONS stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the nation's nursing workforce. We thank the Subcommittee for its consideration of our FY 2010 funding request detailed below.

**Securing and Maintaining an Adequate Oncology Nursing Workforce**

Oncology nurses are on the front lines in the provision of quality cancer care for individuals with cancer – administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing treatment education and counseling to patients and family members, and engaging in myriad

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<sup>1</sup> American Cancer Society. *Cancer Facts and Figures 2008*.  
<http://www.cancer.org/downloads/STT/2008CAFFfinalsecured.pdf>

other activities on behalf of people with cancer and their families. Cancer is a complex, multifaceted chronic disease, and people with cancer require specialty-nursing interventions at every step of the cancer experience. People with cancer are best served by nurses specialized in oncology care, who are certified in that specialty.

As the overall number of nurses is expected to drop precipitously in the coming years, we likely will experience a commensurate decrease in the number of nurses trained in the specialty of oncology. With an increasing number of people with cancer needing high-quality health care, coupled with an inadequate nursing workforce, our nation could quickly face a cancer care crisis of serious proportion, with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the *New England Journal of Medicine* found that nursing shortages in hospitals are associated with a higher risk of complications – such as urinary tract infections and pneumonia, longer hospital stays, and even patient death.<sup>2</sup> Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need, and patient health and well-being could suffer.

Of additional concern is that our nation also will face a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of cancer research nurses, progress against cancer will take longer because of scarce human resources coupled with the reality that some practices and cancer centers' resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, we are concerned that our nation may falter in its delivery and application of the benefits from our federal investment in research.

ONS has joined with others in the nursing community in advocating \$215 million as the FY 2010 funding level necessary to support implementation of the Nurse Reinvestment Act and the range of nursing workforce development programs housed at the U.S. Health Resources and Services Administration (HRSA). Enacted in 2002, the Nurse Reinvestment Act (P.L. 107-205) included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in FY 2008 HRSA received 6,078 applications for the Nurse Education Loan Repayment Program, but only had the funds to award 435 of those applications.<sup>3</sup> Also, in FY 2008 HRSA received 4,894 applications for the Nursing Scholarship Program, but only had funding to support 172 awards.<sup>4</sup>

<sup>2</sup> Needleman J., Buerhaus P., Mattke S., Stewart M., Zelevinsky K. "Nurse-Staffing Levels and the Quality of Care in Hospitals." *New England Journal of Medicine* 346:, (May 30, 2002): 1715-1722.

<sup>3</sup> U.S. Health Resources and Services Administration: Nurse Education Loan Repayment Program: <http://bhpr.hrsa.gov/nursing/loanrepay.htm>. Accessed April 22, 2009.

<sup>4</sup> U.S. Health Resources and Services Administration: Nursing Scholarship Program Statistics: <http://bhpr.hrsa.gov/nursing/scholarship/>. Accessed April 22, 2009.

A number of years ago, one of the biggest factors associated with the shortage was a lack of interested and qualified applicants. Due to the efforts of ONS, our nursing community partners, and other interested stakeholders, the number of applicants is growing. As such, now one of the greatest factors contributing to the shortage is that nursing programs are turning away qualified applicants to entry-level baccalaureate programs, due to a shortage of nursing faculty. According to the American Association of Colleges of Nursing (AACN), U.S. nursing schools turned away 50,000 qualified applicants from baccalaureate and graduate nursing programs in 2008, due to insufficient number of faculty and inadequate resources.<sup>5</sup> Of those potential students, nearly 7,000 were students pursuing a master's or doctoral degree in nursing, which is the education level required to teach. Within the next decade, it is expected that half of all nurse faculty will reach retirement age.<sup>6</sup> Given the expected wave of retirement among faculty, the nurse faculty shortage is only expected to worsen as there are insufficient numbers of candidates in the pipeline to take their places. The number of full-time nursing faculty required to "fill the nursing gap" is approximately 40,000, and, currently, there are less than 20,000 full-time nursing faculty in the system.

With additional funding in FY 2010, the HRSA Workforce Development Programs will have much-needed resources to address the multiple factors contributing to the nationwide nursing shortage, including the shortage of faculty. Advanced nursing education programs play an integral role in supporting registered nurses interested in advancing in their practice and becoming faculty. As such, these programs must be adequately funded in the coming year.

ONS strongly urges Congress to provide HRSA with a minimum of \$215 million in FY 2010 to ensure that the agency has the resources necessary to fund a higher rate of nursing scholarships and loan repayment applications and support other essential endeavors to sustain and boost our nation's nursing workforce. Nurses – along with patients, family members, hospitals, and others – have joined together in calling upon Congress to provide this essential level of funding. The National Coalition for Cancer Research (NCCR), a non-profit organization comprised of 23 national cancer organizations, also is advocating \$215 million in FY 2010 for the Nurse Reinvestment Act. ONS and its allies have serious concerns that without full funding, the Nurse Reinvestment Act will prove an empty promise, and the current and expected nursing shortage will worsen, and people will not have access to the quality care they need and deserve.

#### **Sustain and Seize Cancer Research Opportunities**

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joined with the broader cancer community in advocating a 10% increase (\$33.349 billion) for NIH in FY 2010. This level of investment will

<sup>5</sup> American Association of Colleges of Nursing, "2006-2007 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing," <http://www.aacn.nche.edu/IDS/datarep.htm>, March 2007.

<sup>6</sup> Preliminary Results: "National Survey of Nurse Educators: Compensation, Workload, and Teaching Practices." *National League of Nursing/Carnegie Foundation*. (February 7, 2007) [http://www.nln.org/newsreleases/pres\\_budget2007.htm](http://www.nln.org/newsreleases/pres_budget2007.htm)

allow NIH to sustain and build on its research progress, while avoiding the severe disruption to advancement that could result from a minimal increase. Cancer research is producing amazing breakthroughs – leading to new therapies that translate into longer survival and improved quality of life for cancer patients. In recent years, we have seen extraordinary advances in cancer research, resulting from our national investment, which have produced effective prevention, early detection, and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate \$5.957 billion to the National Cancer Institute (NCI), as well as \$227 million to the National Center for Minority Health and Health Disparities in FY 2010 to support the battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span – from management of patients during illness and recovery, to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest, such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses, such as cancer. ONS joins with others in the nursing community and NCCR in advocating a FY 2010 allocation of \$178 million for NINR.

**Boost Our Nation's Investment in Cancer Prevention, Early Detection, and Awareness**

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our nation does not invest sufficiently in these strategies. The nation must make significant and unprecedented federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our nation, both for today and tomorrow.

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering, at the community level, what is learned from research. Therefore, ONS joins with our partners in the cancer community in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the following FY 2010 funding levels for the following CDC programs:

- \$250 million for the National Breast and Cervical Cancer Early Detection Program;
- \$65 million for the National Cancer Registries Program;
- \$25 million for the Colorectal Cancer Prevention and Control Initiative;
- \$50 million for the Comprehensive Cancer Control Initiative;
- \$25 million for the Prostate Cancer Control Initiative;

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- \$5 million for the National Skin Cancer Prevention Education Program;
- \$10 million for the Ovarian Cancer Control Initiative; and
- \$6 million for the Geraldine Ferraro Blood Cancer Program.

**Conclusion**

ONS maintains a strong commitment to working with Members of Congress, other nursing and oncology societies, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow, and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face in the coming years. By providing the FY 2010 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

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**Testimony of Julie Fleshman, JD, MBA  
President & CEO**

**Pancreatic Cancer Action Network**

**To the House Appropriations Subcommittee on Labor, Health and Human Services,  
Education & Related Agencies**

**On Pancreatic Cancer Research Funding at the National Cancer Institute for  
Fiscal Year 2010**

**Submitted: May 1, 2009**

**Contact: Megan Gordon Don – Director of Government Affairs;  
[mgdon@pancan.org](mailto:mgdon@pancan.org); 202.742.6699**

Mr. Chairman and members of the Subcommittee-

You may recall that last year you heard testimony from Dr. Randy Pausch, a computer science professor at Carnegie Mellon University, author of the widely acclaimed "Last Lecture", which was released on YouTube and later as a book, and at that time, a pancreatic cancer survivor.

Last year, Randy in his frank and humorous manner told you that it was unlikely that he would survive until Father's Day and that his widow, Jai, and three beautiful children, Dillon, Logan, and Chloe would have to mark that holiday without him.

Approximately 75% of pancreatic cancer patients die within the first year of diagnosis. Randy used to call himself a "Pancreatic Cancer Rock Star" given that he had already survived 18 months when he provided his testimony to you. While I am very happy to report that Randy did indeed survive long enough to spend Father's Day with his family, he unfortunately passed soon after on July 25, 2008. With his passing, we lost a dear friend to the pancreatic cancer community, and as I'm sure you would all attest to, a phenomenal pancreatic cancer advocate.

Much has changed in the last year. Unfortunately, the statistics have not. In fact, the statistics have changed little in the last 30 years. Pancreatic cancer is still one of the most deadly cancers and is still the fourth leading cause of cancer related death. It is still true that 95% of all pancreatic cancer patients die within five years of diagnosis. There are still no early detection or treatment tools for this disease. And while pancreatic cancer funding did increase last year, it is also still true that pancreatic cancer research is not funded at a level that will allow true progress.

Part of the problem has been the recent flat or declining biomedical research budgets. Adjusting for inflation, NCI's budget has decreased by nearly \$639 million (13.9 percent) since Fiscal Year 2003. The other problem is that NCI has not made pancreatic cancer – one of our nation's leading cancer killers – a research priority. In fact, the NCI currently allocates just \$87 million for pancreatic cancer research, a mere 2% of its total budget. A percentage that is also unchanged from last year.

We, like many in the cancer and biomedical research communities, worked hard to secure funding increases for the NIH in the Fiscal Year 2009 Omnibus Appropriations bill and in the American Recovery and Reinvestment Act and we are grateful to you for granting the community's requests and providing increases through these bills. The Pancreatic Cancer Action Network took part in these efforts because we believed that increasing funding through these bills would lead to increased funding for pancreatic cancer research. Unfortunately, it does not appear that this hope is turning into a reality.

As the NIH was preparing the Challenge Grants, we were excited about the potential that these grants might bring to the most deadly diseases such as pancreatic cancer. Unfortunately, once we had an opportunity to review the Requests for Applications

(RFAs), we realized that few if any of the grants were actually applicable to pancreatic cancer.

We have also been looking forward to learning more about how NCI plans to use their remaining portion of the stimulus funds. Our hope is that Dr. Niederhuber will dedicate some portion of the funds for the cancers with the highest mortality. Currently, just 8 cancers (ovarian, brain, myeloma, stomach, esophageal, lung, liver, and pancreatic) account for 50 percent of all cancer deaths. For some of these, such as pancreatic and lung cancer, there has been little movement in survival rates in the last 30 years. Unfortunately, while we have not yet seen the actual plan, based on the NCI's statement about it on April 20, 2009, we are concerned that again, our hopes may not turn into a reality.

The mission of the Pancreatic Cancer Action Network is based on hope and on action, so it is in the spirit of both that I am today submitting testimony. I am not only asking that you significantly increase funding for the NCI, but that you also take steps to ensure that NCI places special emphasis on the most deadly cancers, including pancreatic cancer.

While I realize that Congress is reluctant to direct how NCI allocates research dollars, I would argue that something is wrong when one of the deadliest types of cancer receives so little attention. In fact, pancreatic cancer research receives the least amount of NCI funding of any of the top cancer killers. Please see the attached chart of NCI funding for the top five cancer killers and the survival rates for the same cancers. There is no question that funding levels and survival rates are linked.

One of our most significant issues in addition to the overall funding level is that there are relatively few researchers studying pancreatic cancer – including both young investigators and more experienced investigators. While the NCI's commitment to young investigators has increased from 2007 when it awarded zero Career Development Awards (K awards) or Research Training Awards (F and T awards), it still has a long way to go. For example, last year, NCI made nearly 180 awards to young breast cancer researchers and over 70 K, T, or F awards to young researchers in fields of each of the other top five cancer killers (lung, colon, and prostate); only 32 were awarded to young pancreatic cancer researchers. We can and must do better.

The story is much the same for experienced investigators. In 2008, only 32 pancreatic cancer projects were funded at \$500,000 or above, and only 11 projects received at least \$1 million. In contrast, the number of projects funded at \$500,000 or above was 109 for lung, 114 for colon, 237 for breast, and 105 for prostate.

Further, though the pool of researchers that the NCI has funded to conduct pancreatic cancer has expanded, its size is very small, especially when compared to the numbers of researchers funded in the other leading cancer fields. In fact, in 2008 the NCI funded close to 1,600 different investigators in breast cancer research, of whom 231 received multiple awards. As many as 91 of these researchers received an aggregate of \$1 million in funding for their research. By comparison, NCI funded 327 different investigators in



pancreatic cancer research last year, of whom 41 received multiple awards and just 13 received an aggregate of \$1 million for their research.

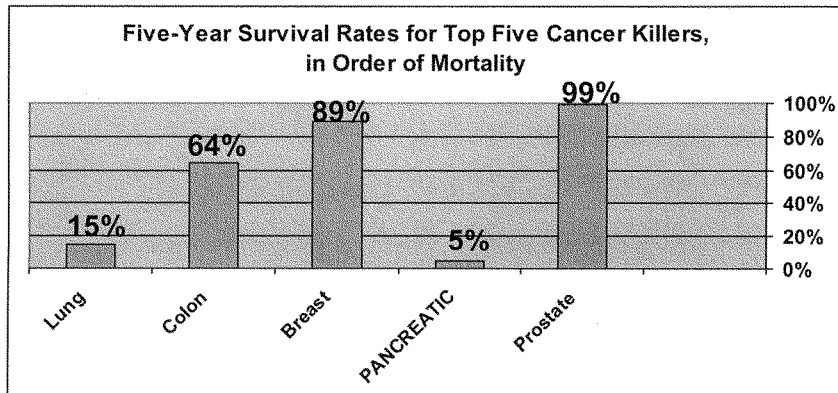
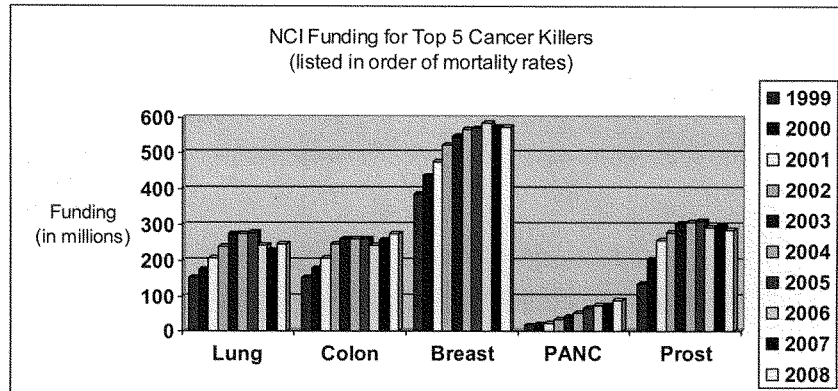
Given that the current five-year survival rate for breast cancer is nearly 90%, it is clear that a similar pipeline of committed and federally funded scientists is needed in pancreatic cancer to help speed advances and medical breakthroughs if we are to hope to finally increase survival beyond 5%.

The fact is that the number of new pancreatic cancer cases and deaths are increasing – not decreasing. The projected number of new pancreatic cancer cases is expected to reach 40,000 by 2010, 50,000 by 2020, 60,000 by 2030, and 70,000 by 2040. As stated above, while overall cancer death rates have significantly declined, the five-year survival rates for pancreatic cancer have remained largely unchanged in the last 30 years. If we do not take steps to address this issue now, 95 percent of these patients will continue to hear their diagnosis expressed as a death sentence.

Sadly, it is also a fact that for too long, the broader scientific research community has faced the challenge of doing more with less. While they have achieved some important successes, the funding crisis has fostered an environment of focusing on “safe bets.” Compared to most other cancers, we know relatively little about pancreatic cancer. More research is needed in the basic biology of the disease to understand how it starts and why it spreads so rapidly. Therefore, pancreatic cancer research does not fall into a “safe bet” category. It falls into the category of high risk/high reward.

The time has come to not only fund new progress and give our researchers the opportunity to do more with more, but to also find new ways to encourage the research community to tackle the hardest and most complex problems. As Randy mentioned in his testimony last year, it is by solving the hardest problems that we will likely see the greatest rewards for the entire field. On behalf of the tens of thousands of pancreatic cancer patients who die without a chance, including Dr. Randy Pausch, I am asking that you not only inject significant new funding into the cancer research community, but that you also issue a challenge to the NCI to focus on the hardest problems by placing special emphasis on finding answers for the most deadly cancers, including pancreatic. Doing so will not only fuel progress, but will also generate jobs and stem the current trend of losing American-trained researchers to other countries more willing to invest in scientific research.

We therefore join with our partners in the One Voice Against Cancer (OVAC) coalition to ask that you provide \$5.96 billion in funding for the NCI in Fiscal Year 2010 – an increase of \$993 million (20%) over Fiscal Year 2009. We recognize that this is a significant request. However, the reality is that this is the minimum amount needed to make true progress on all forms of cancer, including pancreatic and the other cancers for which we have yet to see significant improvement in survival.



**Written Testimony Submitted to the House of Representatives  
Labor, Health and Human Services, and Education Appropriations Subcommittee  
Regarding FY 2010 Funding for Global Health Research and Development  
Christopher J. Elias, MD, MPH  
President and CEO, PATH  
Tel: 206.285.3500  
celias@path.org  
April 30, 2009**

**Overview:** PATH appreciates the opportunity to submit written testimony to the House Labor, Health and Human Services, and Education Appropriations Subcommittee. PATH is a US-based international nonprofit organization that creates sustainable, culturally relevant solutions that enable communities worldwide to break longstanding cycles of poor health. By collaborating with diverse public- and private-sector partners, we help provide appropriate health technologies and vital strategies that change the way people think and act. Our work improves global health and well-being.

The broad, ongoing, and successful struggle to improve global health relies on the availability of health interventions and technologies designed to prevent, diagnose, and treat disease. Although some effective interventions already exist, many more will be necessary if existing gains against infectious disease and other global health burdens are to be maintained and expanded. The drugs currently available for use against diseases that disproportionately impact the developing world are often too expensive for use in the developing world, and are also subject to disease resistance. Vaccines for many of these infectious diseases do not yet exist and diagnostic equipment, vaccine delivery devices, microbicides, contraceptives, and other health technologies appropriate for the developing world are in many cases not available or affordable. Achieving sustainable progress in the struggle to improve global health will require developing new health technologies, and creating infrastructures that facilitate their availability to those who need them most.

Several programs funded in the Labor, Health and Human Services, and Education appropriations bill make a particularly critical contribution to point-of-care diagnostics, a research area that is key to improving health in the developing world. In low-resource settings, where many diagnostic tests are difficult to perform and laboratories are often inaccessible, there is a great opportunity to make significant improvements to global health through the development and use of appropriate point-of-care diagnostics. In poor countries, health care facilities can be far away, serving widely dispersed populations. Specialized equipment, personnel, and safe waste-disposal systems are often not available. Without diagnostic testing, health care professionals have to rely on just evaluating symptoms to diagnose and treat illness—an imperfect method given the similarity of symptoms between many diseases. This lack of clarity puts individuals, communities, and the world in danger. Incorrect diagnoses can harm people and even cost lives. And from a global perspective, ineffectively treated disease can become a starting point for epidemic or pandemic outbreaks.

Fortunately, there is an array of promising new tests in the pipeline—inexpensive, portable, easy-to-use diagnostics that are practical at even small, local health centers, and which can deliver results the same day. Some are new takes on established technologies like the home

pregnancy test. Others are exciting scientific advances. Effective diagnosis at, or near, the point of care enables better application of available treatment, avoids overuse of antibiotics that can promote resistant strains of pathogens, and allows health care workers to track outbreaks and mobilize resources quickly.

The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) continue to make significant contributions to the development of new health technologies. Generally speaking, NIH carries out the critical basic and preclinical research that provides the foundation for new product discovery and development, supports and conducts clinical trials of promising products, and develops the in-country research capacity of developing world partners. CDC monitors and tracks infectious diseases worldwide, provides those involved in the control and prevention of these diseases with the critical intelligence they need to implement their programs effectively, supports researchers in their work by helping to direct their efforts towards the areas with the greatest potential for benefit, and warns researchers when new trends or disease strains emerge.

Point-of-care diagnostics are one of the most critical global health technologies whose development of testing is supported by NIH and CDC. One example of this support is the ongoing and successful partnership between the NIH's National Institute of Biomedical Imaging and Bioengineering (NIBIB) and PATH. Working together with an investment from NIH/NIBIB, PATH formed the Center for Point-of-Care Diagnostics for Global Health (GHDx Center), a diagnostics research, development, testing, needs assessment and training program that works to improve the availability, accessibility, and affordability of essential point-of-care diagnostic tests for use in low-resource settings around the world. The GHDx Center, managed by PATH in collaboration with its partners at the University of Washington, is on the cutting edge of developing new diagnostic tools that can be used in developing countries to quickly and accurately diagnose diseases that disproportionately impact the developing world, but which until now have been difficult to accurately diagnose without laboratory facilities or extensively trained medical workers.

The GHDx Center focuses its work on four main areas that encompass the breadth of the health technology product development cycle. The GHDx Center performs and supports clinical needs assessments that help diagnostics developers target the most pressing global health challenges and increase the likelihood of product success. It supports exploratory technology projects that could have a significant positive impact on public health outcomes. It conducts laboratory and field-based clinical testing of prototype point-of-care diagnostics. Finally, the GHDx Center—in a program led by the University of Washington Department of Global Health and Department of Medicine (Division of Infectious Diseases)—trains individuals with varied experience and backgrounds from the fields of assay and device development, clinical laboratories, and disease specialties, with the objective of creating a networked group of researchers trained in state-of-the-art technology that address the challenges for global health in low-resource settings.

This extraordinarily promising new program would not have been possible without NIH support, and PATH thanks the subcommittee for its wise investments in NIH. Without robust funding for NIH and CDC, much of the cutting-edge research and development being performed on point-of-care diagnostics for the developing world would not be taking place. While many

commercial and nonprofit groups are working on diagnostic technologies, they are not necessarily doing so with an eye toward the developing world. For example, their efforts often target diseases that mainly concern wealthier countries, or they assume that sophisticated laboratories and trained personnel will be available to complement and operate their diagnostics. In contrast, diagnostic technologies for malaria, enteric diseases, hepatitis b, and other conditions whose heaviest burden falls on the developing world, or which can be used in resource-poor conditions where laboratory equipment are scarce, do not have a significant commercial market that incentivizes research and development. Without investment by the US government, efforts to develop these diagnostic technologies—and by doing so improve care and reduce the development of drug resistance—would be hindered significantly. Expanding funds for these agencies would provide a powerful boost to point-of-care diagnostic development and availability.

Continued progress in our nation's effort to improve global health requires the development of new tools and technologies. Point-of-care diagnostics are an important component of the portfolio of needed tools and technologies, and the development of those tools and technologies is heavily reliant on federal support. For this reason, we respectfully request that the Subcommittee expand funding for research and development at NIH and CDC. We very much appreciate the Subcommittee's consideration of our views, and we stand ready to work with Subcommittee members and staff on these and other important tropical disease matters.

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STATEMENT BY

ANN PEEL

PRIVATE CITIZEN, BETHESDA, MARYLAND

BEFORE

THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

CONCERNING

AMYLOIDOSIS

March 18, 2009

**Summary:** The testimony asks the Committee to include report language calling for additional steps to be taken on the diagnosis, treatment and research on the rare and deadly disease amyloidosis. The testimony also asks that additional research and treatment equipment for amyloidosis be provided for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

Mr. Chairman, I appreciate the opportunity to submit testimony to the Committee on the life threatening disease amyloidosis. I ask that you continue to include language in the Committee's report for fiscal year 2010 drawing attention to amyloidosis. I also request that you recommend assistance for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

Nearly five years ago, I was diagnosed with the life-threatening disease primary amyloidosis. I had never heard of the disease amyloidosis. I was not alone. It is a disease that is often misdiagnosed or diagnosed too late.

Amyloidosis, which is often fatal, leads to heart, kidney, liver and other organ failure. Amyloidosis can literally kill people before they know what hit them. Left untreated there is an average survival rate from the time of diagnosis of about 15 months.

Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis. The small number of those with amyloidosis who are lucky enough to obtain treatment face the risk of high dose chemotherapy and stem cell replacement.

Less than one percent of the U. S. population has been identified to have this disease. Many feel that the disease is vastly under diagnosed, especially in the African-American community.

I have successfully obtained treatment for amyloidosis. Now I want to devote time to use my experience to help others.

#### **WHAT IS AMYLOIDOSIS?**

Amyloidosis occurs when cells malfunction and produce proteins that deposit on organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace.

In addition to primary amyloidosis, there are also cases of inherited or familial amyloidosis and secondary or reactive amyloidosis. All three types of amyloidosis, left undiagnosed or untreated, are fatal.

There is no explanation for how or why amyloidosis develops and there is no known cure.

#### **HOW IS AMYLOIDOSIS TREATED?**

Boston University School of Medicine and other centers for amyloidosis treatment have found that large dose intravenous chemotherapy followed by stem cell replacement, or rescue, is an effective treatment in many patients. Abnormal bone marrow cells are killed through high dose chemotherapy and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

I am part of a clinical trial and have gone through this procedure twice.

The high dose chemotherapy and stem cell rescue has increased the remittance and long term survival rate dramatically: increasing from two percent to almost 50 percent the number of patients with total remission.

#### **WHAT NEEDS TO BE DONE?**

Only through more research is there hope of further increasing that survival rate and finding treatments to help more patients. Research needs to be done to develop targeted treatments that will specifically attack the amyloid protein produced in the bone marrow. Additional funding for research and equipment is needed to accomplish this task.

Timely diagnosis is also of great concern. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

Early treatment is the key to success. More needs to be done in this area to alert health professionals to identify this disease.

#### **WHAT STEPS HAVE BEEN TAKEN?**

Through the leadership of this Committee and the further involvement of the U. S. Government, a number of positive developments have occurred.

- The National Institutes of Health has increased its involvement in amyloidosis. Through a series of symposiums, reports and heightened staff interest, NIH has begun to take a leadership role.
- There has been increased basic and clinical research at the Amyloid Treatment and Research Program: a model for the disease is under development; factors that cause protein misfolding are being identified; and new clinical trials are underway.
- Increased Federal funding for research, equipment and treatment has been another important element. This is essential to speed the pace of discovery for basic research.

#### **WHAT ARE THE NEXT STEPS?**

Mr. Chairman, we ask that the Committee do three things to help address this deadly disease.

- First, continue language in your report identifying amyloidosis as an important concern and encouraging more research to find a cure.



- Second, continue to encourage the Centers for Disease Control and the National Institutes of Health to educate the American public and medical profession on the need to diagnose this disease at an early stage.
- Third, provide fiscal year 2010 funds within the Department of Health and Human Services for equipment and related assistance for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center to assist in methods for treating and curing this tragic disease.

The United States Congress and the Executive branch working together are key to finding a cure for and alerting people to this terrible disease. I ask for your support in helping me turn what has been my life-threatening experience into hope for others.

Thank you for your consideration.

**Prevent Blindness America**  
**Written Testimony to the House Labor-Health and Human Services (LHHS)**  
**Appropriations Subcommittee**  
**Regarding Fiscal Year 2010 Funding For Vision Related Programs**  
**Submitted by: Hugh Parry, President & CEO, Prevent Blindness America**  
[\(312\) 363-6010](mailto:hparry@preventblindness.org)  
**May 1, 2009**

**Funding Request Overview**

Prevent Blindness America (PBA) appreciates the opportunity to submit written testimony for the record regarding fiscal year (FY) 2010 funding for vision related programs. As the nation's leading non-profit, voluntary organization dedicated to preventing blindness and preserving sight, PBA maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. PBA respectfully requests that the Subcommittee provide the following allocations in Fiscal Year (FY) 2010 to help promote eye health and prevent eye disease and vision loss:

- \$4.5 million for the Vision Health Initiative at the Centers for Disease Control and Prevention (CDC);
- \$32.4 billion for the National Institutes of Health (NIH) to support biomedical research; and
- \$736 million for the National Eye Institute (NEI).

As you may know, a bipartisan group of 21 Representatives have submitted a letter to the Subcommittee in support of a \$4.5 million FY 2010 allocation for the Vision Health Initiative; this effort was spearheaded by Representatives Gene Green, David Price, and Ileana Ros-Lehtinen, co-chairs of the Congressional Vision Caucus.

**Introduction and Overview**

Vision-related conditions affect people across the lifespan from childhood through elder years. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to ten percent of preschool age children. Vision disorders (including amblyopia ("lazy eye"), strabismus ("cross eye"), and refractive error) are the leading cause of impaired health in childhood.

Of serious concern is that the NEI reports "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."<sup>1</sup> Among Americans age 40 and older, the four most common eye diseases causing

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<sup>1</sup> "Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America,"

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vision impairment and blindness are age-related macular degeneration (AMD), cataract, diabetic retinopathy, and glaucoma.<sup>2</sup> Refractive errors are the most frequent vision problem in the U.S. – an estimated 150 million Americans use corrective eyewear to compensate for their refractive error.<sup>3</sup> Uncorrected or under-corrected refractive error can result in significant vision impairment.<sup>4</sup>

While half of all blindness can be prevented through education, early detection, and treatment, it is estimated that the number of blind and visually impaired people will double by 2030, if nothing is done to curb vision problems. To curtail the increasing incidence of vision loss in America, PBA advocates sustained and significant federal funding for vision research and application, as well as resources for programs that help promote eye health and prevent eye disease, vision loss, and blindness. We thank the Subcommittee for its consideration of our specific FY 2010 funding requests, which are detailed below.

**CDC's Vision Health Initiative: Helping to Save Sight and Save Money**

The financial costs of vision impairment to our country's fiscal health are staggering. PBA estimates that the annual costs of adult vision problems in the U.S. are approximately \$51.4 billion.<sup>5</sup> The annual cost of untreated amblyopia – reduced vision in an eye that has not received adequate use during early childhood – is approximately \$7.4 billion in lost productivity.<sup>6</sup> NEI estimates that in 2003 the total direct and indirect costs of visual disorders and disabilities in the U.S. were approximately \$68 billion dollars, and with each passing year these costs continue to escalate.<sup>7</sup> Vision care services consistently have been found to help prevent blindness, reduce vision loss, improve quality of life and well-being, increase productivity, and reduce costs and burdens on the nation's health care system. Therefore, the nation must increase access to – and awareness of the importance of – vision screenings and linkage to appropriate care for at-risk and underserved populations, as is provided by the CDC's Vision Health Initiative.

The CDC reports that “vision disability is one of the top ten disabilities among adults 18 years and older and the single most prevalent disabling condition among children.”<sup>8</sup> Effective public

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Prevent Blindness America and the National Eye Institute, 2008.

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> “The Economic Impact of Vision Problems,” Prevent Blindness America, 2007.

<sup>6</sup> “Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America,” Prevent Blindness America, 2008.

<sup>7</sup> Ellwein Leon. Updating the Hu 1981 Estimates of the Economic Costs of Visual Disorders and Disabilities.

<sup>8</sup> “Improving the Nation's Vision Health: A Coordinated Public Health Approach,” Centers for Disease Control, 2006.

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health initiatives can dramatically decrease the number of Americans who have vision loss or low vision. Initially funded by Congress in FY 2003, the CDC's Vision Health Initiative program has worked in a cost-effective way to identify, screen, and link to appropriate care individuals at risk for vision loss. This public-private partnership combines the resources of the CDC, chronic disease directors, state and local Agencies on Aging, and non-profit organizations such as PBA. Highlights of the significant work of the CDC's Vision Health Initiative include:

- ✓ Support for the eye evaluation component of the National Health and Nutrition Examination Survey (NHANES) that provides current, nationally representative data and help assess progress for vision objectives contained within Healthy People 2010 and the future efforts for Healthy People 2020.
- ✓ Development of the first optional Behavioral Risk Factor Surveillance System (BRFSS) vision module and introducing it into state use in 2005 to gather information about access to eye care and prevalence of eye disease and eye injury. Five states implemented the module in 2005, and 11 states began using the module in 2006.
- ✓ Utilization of applied public health research to address the economic costs of vision disorders and develop cost-effectiveness models for eye diseases among various populations. Estimating the true economic burden is essential for informing policymakers and for obtaining necessary resources to develop and implement effective interventions.
- ✓ Providing data analyses and a systematic review of interventions to promote screening for diabetic retinopathy and reviewing access to and utilization of vision care in the U.S.
- ✓ Developing best practices for the integration of vision care services with community health centers, as well as methods for linking clients to appropriate and needed care.
- ✓ Aiding in the translation of science into programs, services, and policies and in coordinating service activities with partners in the public, private, and voluntary sectors.

In FY 2009, PBA requested \$4.5 million to sustain and expand the Vision Health Initiative. In the final FY 2009 Omnibus Appropriations Act, Congress allocated \$3.222 million. PBA understands the budgetary challenges facing Congress and the nation and, as such, appreciates this much-needed funding. However, with the demographics of eye disease, we feel strong that a greater investment in the Vision Health Initiative must be made, so we can mount an adequate effort to address the growing public health threat of preventable vision loss among older Americans, low-income, and underserved populations.

To that end, PBA again respectfully requests the Subcommittee provide a \$4.5 million allocation for the Vision Health Initiative. Increased FY 2010 funding for this important program will support additional vision screenings, increased public awareness efforts regarding risk of vision loss, develop best practices for linkage to care, and the expansion of eye disease surveillance and evaluation systems, which will help ensure our nation has much-needed epidemiological data

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regarding overall burden and high-risk populations, so we can best formulate and assess strategies to prevent and reduce the economic and social costs associated with vision loss and eye diseases.

**Advance and Expand Vision Research Opportunities**

Our nation has benefited from past federal investment in biomedical research at the NIH. Unfortunately, due to flat funding over the past six appropriations cycles, NIH has lost 14 percent of its purchasing power. While we commend Congress for the \$10.4 billion in funding provided in the American Recovery and Reinvestment Act, PBA joins the broader vision community in advocating a seven percent increase (\$32.4 billion) for NIH in FY 2010. This level of investment will allow NIH to sustain and expand its research progress and avoid the potential disruption of vital research that could result from a minimal increase.

PBA also calls upon the Subcommittee to provide a specific allocation of \$736 million for the NEI to bolster its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Celebrating 40 years of service this year, NEI is a leading institute in translating basic research into clinical practice. Just as NIH has seen a decline in purchasing power, so too has the NEI, an overall decrease of 18 percent in the last six appropriations cycles. In FY 2009, NEI's funding level of \$688 million reflected just one percent of the estimated \$68 billion annual costs of eye disease and vision impairment. Despite significant funding challenges, NEI has maintained its impressive record of breakthroughs in basic and clinical research that have resulted in treatments and therapies to save and restore vision and prevent eye disease. However, NEI will be challenged further, as 2010 begins the decade in which more than half of the 78 million Baby Boomers will turn 65 and be at greatest risk for developing aging eye disease. Adequate funding to NEI is a cost-effective investment in our nation's health, as it can delay, save, and prevent eye disease-related expenditures, especially to the Medicare and Medicaid programs.

**Investing in the Vision of Our Nation's Most Valuable Resource – Children**

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern, due to the fact that, if left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.<sup>9</sup> Approximately 80% of

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<sup>9</sup> "Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America," Prevent Blindness America, 2008.

*Prevent Blindness America  
Written Testimony to the House Labor-Health and Human Services  
Appropriations Subcommittee  
Regarding Fiscal Year 2010 Funding For Vision Related Programs  
May 1, 2009*

what a child learns is done so visually.<sup>10</sup> As such, good vision is essential for educational progress, proper physical development and athletic performance, and healthy self-esteem in growing children. Yet, according to a CDC report, only one in three children in America has received eye care services before the age of six.

Vision screening is an appropriate and essential element of a strong public health approach to children's vision care; the sooner vision problems are identified, the faster they can be addressed. As you know, the Maternal and Child Health Bureau (MCHB) oversees the Maternal and Child Health Services state Title V ("Title V") Block Grant program. As a condition of funding under Title V, states are required to report on certain measures to the MCHB. PBA urges the Subcommittee to support the development and implementation of a nation-wide Title V core performance measure related vision screening. A core performance measure regarding vision screening will help ensure that more children receive comprehensive eye examinations at a young age and provide specific information to MCHB and other public health officials regarding the progress of the programs and identify areas where improvement can be made to provide better vision care to children served by the Title V program. Specifically, we hope the Subcommittee will include language in the report accompanying the FY 2010 LHHS appropriations measure that expresses support for MCHB's work in this area.

We are pleased that the Head Start program currently requires children to be screened for vision problems. Unfortunately, there are no procedures for training, tracking, or even conducting the screening. As such, without a national uniform standard, many Head Start enrollees are falling through the cracks and vision problems are not being identified in this already often underserved and at-risk population. PBA stands ready to work with Head Start, the Congress, and other stakeholders to ensure that all Head Start enrollees receive vision screening services and other related resources available to them in their community. PBA respectfully requests that the Subcommittee include language in the report accompanying the FY 2010 LHHS appropriations measure that encourages collaborations and initiatives within the Head Start program to ensure that such screenings are delivered and provided in a manner that promotes consistency and quality in protocol and administration.

#### Conclusion

On behalf of PBA, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding FY 2010 funding for the CDC's Vision Health Initiative, NIH, and NEI. Please know that PBA stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to – and consideration of – our requests.

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<sup>10</sup> Ottar WL, Scott WK, Holgado SI. Photoscreening for amblyogenic factors. *J Pediatr Ophthalmol Strabismus*. 1995; 32:289-295.

TESTIMONY OF

Mr. Rino Aldrighetti

President

PULMONARY HYPERTENSION ASSOCIATION

ON BEHALF OF THE

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REGARDING

FISCAL YEAR 2010 APPROPRIATIONS FOR CDC, NIH AND  
HRSA

SUBMITTED TO THE  
HOUSE LABOR-HHS-EDUCATION APPROPRIATIONS  
SUBCOMMITTEE

April 28, 2009

SUMMARY OF FY 2010 RECOMMENDATIONS:

- A 7% increase for the National Institutes of Health (NIH) and National Heart, Lung and Blood Institute (NHLBI) and the establishment of a pulmonary hypertension research network through the Institute.
- Funding within the Centers for Disease Control and Prevention (CDC) for an expanded pulmonary hypertension (PH) awareness and education program.
- \$30 million for the Health Resources and Services Administration's "Gift of Life" Donation Initiative.

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association (PHA).

I would like to extend my sincere thanks to the Subcommittee for your past support of pulmonary hypertension (PH) programs at the National Institutes of Health, Centers for Disease Control and Prevention, and Health Resources and Services Administration. These initiatives have opened many new avenues of promising research, helped educate hundreds of physicians in how to properly diagnose PH, and raised awareness about the importance of organ donation and transplantation within the PH community.

In addition, I want to commend the Subcommittee for actively addressing the current backlog in Social Security Disability applications at the Social Security Administration. Many PH patients end up applying for disability coverage, and streamlining the benefits process would go a long way toward improving the quality of life for our most in-need families.

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against a devastating disease. Pulmonary hypertension is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as: collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, or liver disease. PH does not discriminate based on race, gender, or age. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting. Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, making it impossible to receive a necessary heart or lung transplant.

PH is chronic and incurable with a poor survival rate. Fortunately, new treatments are providing a significantly improved quality of life for patients with some managing the disorder for 20 years or longer.

Nineteen years ago, when three PH patients found each other, with the help of the National Organization for Rare Diseases, and founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland.

I am pleased to report that we are making good progress in our fight against this deadly disease. Six new therapies for the treatment of PH have been approved by the FDA in the past 10 years.



Today, PHA includes:

- Over 10,000 patients, family members, and medical professionals as members and an additional 34,000 supporters and friends.
- A network of over 200 patient support groups.
- An active and growing patient-to-patient telephone helpline.
- Three research programs that, through partnerships with the National Heart, Lung and Blood Institute and the American Thoracic Society, have committed more than \$7.5 million toward PH research as of December, 2008.
- Numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension – published quarterly and distributed to all cardiologists, pulmonologists, and rheumatologists in the U.S.
- A website dedicated to providing educational and support resources to patients, medical professionals, and the public. Thanks to support from the Centers for Disease Control, PHA's online resources now include the *PHA Online University* which provides PH-specific continuing education opportunities to medical professionals.

#### THE PULMONARY HYPERTENSION COMMUNITY

Mr. Chairman, I am privileged to serve as the President of the Pulmonary Hypertension Association and to interact daily with the patients and family members who are seeking to live their lives to the fullest in the face of this deadly, incurable disease.

Carl Hicks is a former Army Ranger and a retired Colonel who lead the first battalion into Iraq during the first Iraq war. Every member of his family was touched by pulmonary hypertension after the diagnosis of his daughter Meghan in 1994. I share their story here, in Carl's own words:

*We're sorry Colonel Hicks, your daughter Meghan has contracted primary pulmonary hypertension. She likely has less than a year to live and there is nothing we can do for her.*

"Those words were spoken in the spring of 1994 at Walter Reed Army Medical Center. They marked the start down the trail of tears for a young military family that, only hours before, had been in Germany. My family's journey down this trail hasn't ended yet, even though Meghan's fight came to an end with her death on January 30<sup>th</sup>, 2009. She was 27.

Pulmonary hypertension (PH) struck our family, as it so often does, without warning. One day, we had a beautiful, healthy, energetic twelve-year old gymnast, the next, a child with a death sentence being robbed of every breath by this heinous disease. The toll of this fight was far-reaching. Over the years, every decision of any consequence in the family was considered first with regards to its impact on Meghan and her *struggle for breath*.

The investment made by our country in my career was lost, as I left the service to stay nearer my family. The costs for Meghan's medical care, spread over the nearly fourteen years of our fight, ran well into the seven figures. Meghan even underwent a heart and dual-lung transplant. These challenges, though, were *nothing* compared to the psychological toll of losing Meghan who had fought so hard for something we all take for granted, a breath of air."

\* \* \*

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. As Meaghan's story illustrates, however, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research holds the promise of a better tomorrow.

Thanks to congressional action, and to advances in medical research largely supported by the NHLBI and other government agencies, PH patients have an increased chance of living with their pulmonary hypertension for many years. However, additional support is needed for research and related activities to continue to develop treatments that will extend the life expectancy of PH patients beyond the NIH estimate of 2.8 years after diagnosis.

#### FY 2010 APPROPRIATIONS RECOMMENDATIONS

##### *A) NATIONAL HEART, LUNG AND BLOOD INSTITUTE*

Recently, the World Health Organization's Fourth World Symposium on Pulmonary Hypertension brought together PH experts from around the world. According to these leading researchers, we are on the verge of significant breakthroughs in our understanding of PH and the development of new and advanced treatments. Fifteen years ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of six FDA approved therapies. Recognizing that we have made tremendous progress, we are also mindful that we are a long way from where we want to be in 1) the management of PH as a treatable chronic disease, and 2) a cure.

One crucial step in continuing the progress we have made in the treatment of PH is the creation of a pulmonary hypertension research network. Such a network would link leading researchers around the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the opportunities to collaborate on studies and to strengthen the interconnections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network.

In order to maintain the important momentum in pulmonary hypertension research that has developed over the past few years, and to create a much needed pulmonary hypertension research network, the Pulmonary Hypertension Association encourages the Subcommittee to provide the National Institutes of Health, particularly the NHLBI, with a 7 % increase in funding in FY 2010.

We are very aware of the strong need for robust support of the NIH. A few years ago, leading PH researchers submitted a proposal to NIH focused on the blood thinning drug warfarin as a possible new treatment option for PH. This concept was greeted enthusiastically within our community because it could reduce the cost of treating PH from hundreds of thousands of dollars a year to hundreds

of dollars. The proposal received an excellent score, but did not make the declining NIH payline. It is critical that studies like these move forward in the future.

*B) CENTERS FOR DISEASE CONTROL AND PREVENTION*

PHA applauds the Subcommittee for its leadership over the years in encouraging the Centers for Disease Control and Prevention to initiate a Pulmonary Hypertension Education and Awareness Program. We know for a fact that Americans are dying due to a lack of awareness of PH, and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations

Mr. Chairman, we are grateful to the CDC for providing \$238,000 in support of a pulmonary hypertension awareness program in FY09. By educating physicians and patients about pulmonary hypertension, this funding will save lives. We encourage the Subcommittee to continue its support for PH awareness activities through the CDC in FY10.

*C) "GIFT OF LIFE" DONATION INITIATIVE AT HRSA*

Mr. Chairman, PHA applauds the success of the Health Resources and Services Administration's "Gift of Life" Donation Initiative. This important program is working to increase organ donation rates across the country. Unfortunately, the only "treatment" option available to many late-stage PH patients is a lung, or heart and lung, transplantation. This grim reality is why PHA established "Bonnie's Gift Project."

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use "Bonnie's Gift" as a way to disseminate information about PH, transplantation, and the importance of organ donation, as well as organ donation cards, to our community.

PHA has had a very successful partnership with HRSA's "Gift of Life" Donation Program in recent years. Collectively, we have worked to increase organ donation rates and raise awareness about the need for PH patients to "early list" on transplantation waiting lists. For FY 2010, PHA recommends an appropriation of \$30 million for this important program.

**Statement of the Religious Coalition for Reproductive Choice  
in Support of Teen Pregnancy and Disease Prevention Programs**

**House Appropriations  
Subcommittee on Labor, Health and Human Services, Education,  
and Related Agencies**

**Submitted for the Record  
May 25, 2009**

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Mr. Chairman and Members of the Committee:

The Religious Coalition for Reproductive Choice (RCRC) appreciates this opportunity to submit testimony. We strongly support President Obama's proposal to eliminate the dedicated funding streams for abstinence-only programs and to support proven teen pregnancy prevention programs.

RCRC is an interfaith alliance of national mainstream religious organizations dedicated to ensuring access to reproductive health care and achieving reproductive justice. For more than 35 years, RCRC has brought together 40 national religious and religiously affiliated organizations from 15 denominations and traditions. Our membership includes the Episcopal Church, the Presbyterian Church (USA), the United Church of Christ, the United Methodist Church (General Board of Church and Society and Women's Division, General Board of Global Ministries), the Unitarian Universalist Association of Congregations; and Reform, Reconstructionist and Conservative Judaism.

As faith communities, we are committed to sex education in our public schools that empowers and protects young people, honors diverse values, and promotes the highest ethical standards. Religious Americans overwhelmingly favor responsible sex education that is complete, age appropriate and includes accurate information about abstinence and contraception.

Abstinence-only-until-marriage programs cannot offer this and moreover they are ineffective. These programs often are dishonest and scientifically inaccurate. There

is no justification for endangering the health and well-being of the young people of our nation for the sake of a very parochial moral vision.

In fact, while there certainly is great value in adolescents postponing sex until they are mature, federal policies that withhold important life saving information about STDs or HIV/AIDS or other aspects of reproductive health raise serious moral and ethical questions. Young people have a basic human right to complete and accurate HIV/AIDS and sexual health information. Without it they will be unable to realize the highest attainable standard of health and for some, their futures will be compromised with disease or unintended pregnancy.

#### **Support of religious communities for comprehensive sexuality education**

Major faith traditions representing millions of Americans support comprehensive sex education. In keeping with our nation's constitutional guarantee of freedom of religion, they oppose civil laws that would impose specific religious views about sexuality education on all Americans.

These faith communities take seriously their duty to instill a set of religious and moral values that will help guide young people to responsible life choices. They believe that it is the role of government to ensure that the nation's youth receive the facts - unblemished by ideology - that will protect them from disease and unintended pregnancy.

RCRC has compiled excerpts of official statements of religious denominations and traditions on the importance of sexuality education. We have attached a copy of the complete document, Religious Communities and Sexuality Education: In the Home, In the Congregation, In the Schools, for your review. But to give you a brief taste of these statements, please consider the following:

##### **United Methodist Church:**

"Children, youth and adults need opportunities to discuss sexuality and learn from quality sex education materials in families, churches and schools."

##### **United Synagogue of Conservative Judaism**

"...supports comprehensive sex education...calls upon the U.S. Congress to cease funding of abstinence only education."

##### **Presbyterian Church (U.S.A.)**

"...supports...comprehensive school health education that includes age and developmentally appropriate sexuality education in all grades..."

**Muslim Women's League**

"Sex education can be taught in a way that informs young people about sexuality in scientific and moral terms."

**Episcopal Church**

"...we encourage the members of this Church to give strong support to responsible local public and private school programs of education in human sexuality."

**Need for attention to disease prevention**

Although the President's budget does not link the issues of teen pregnancy prevention and disease prevention, we know that the most effective programs are comprehensive and do connect the two. According to the American Social Health Association, each year 9 million new cases of STDs occur among young people aged 15-24. Sexually active youth have the highest STD rates of any age group in the country. Young people are at greatest risk for STDs because, as a group, they are more likely to have unprotected sex.

The health consequences of STDs include chronic pain, infertility, cervical cancer and increased vulnerability to HIV, the virus that causes AIDS. The transmission of STDs to babies — prenatally, during birth or after — can cause serious life-long complications and even death.

We urge the appropriations committee to include language that expands the requirement for funded programs to include disease prevention.

**How did you learn about sex?**

This past year, RCRC put out a request to "tell us your story: how did you learn about sex?" We received well over 400 responses from individuals around the country age 17 through 94. These replies offer thoughtful reflections and often intimate, sometimes painful, glimpses into personal lives.

Among other things, we found that what you learn — or don't learn — as a young person can have life-long repercussions. And abstinence-only programs, by their design, leave out important health information.

If I had known what sex was, I would have understood what was happening to me when I was molested by a male relative beginning at age 8. — Deborah,  
45

I wish I'd learned what intercourse was and how easy it is to get pregnant. – anon, 79

I wish I'd learned about STDs and the way in which they can be transmitted. I was under the impression that oral sex was safe, since you couldn't get pregnant from it. - Miranda, 26

The good girl/bad girl images prevalent when I was young only served to instill a great deal of fear in me, which negatively impacted on my marriage for years. – anon, 57

### **Communities of color**

According to former Surgeon General Joycelyn Elders, the black community's "problem with sexuality has contributed more to the poverty in the black community than anything else in our society. A pregnant teenager who does not finish high school or marry has an 80% likelihood of being poor." She challenged Congress to "stop legislating morals and start teaching responsibility." Abstinence-only education has been proved through studies and in harsh reality to be a horrible failure. A low income woman is four times as likely to have an unintended pregnancy, five times as likely to have an unintended birth and more than four times as likely to have an abortion as her higher-income counterpart. It is the poor and communities of color who suffer from illogical and ineffective public policy. The denominations and people of faith that comprise RCRC agree with Dr. Elders that "If I could make any changes at all to the current health care system, you know I would start with education, education, education. You can't educate people that are not healthy. But you certainly can't keep them healthy if they're not educated."

RCRC addresses these issues through our National Black Church Initiative, a program begun in 1997 to "break the silence" about sex and sexuality in the African American community. The initiative assists Black clergy and laity in addressing teenage pregnancy, sexuality education and reproductive health within the context of African American religion and culture. We have worked in over 700 churches providing our "Keeping It Real!" faith based sexuality education curriculum to more than 7,000 young men and women. We have a similar faith based initiative, La Iniciativa Latina (LIL), which provides model programs on sexuality and reproductive health for Latino youth, adults and clergy in the context of Latino values, religion and culture.

But the answer to the nation's high rate of unintended pregnancy and pandemic of sexually transmitted diseases does not rest with churches and non-profit organizations alone. Public schools must be part of the solution. We are morally compelled to empower our young people with the knowledge to make responsible decisions. As Dr. Elders so succinctly stated, "Vows of abstinence break more easily

than latex condoms.” According to the CDC’s National Center for Health Statistics, in 2002, the pregnancy rates for black and Hispanic teenagers were each more than two and one-half times the rate for white teenagers. This is the reality.

One of the most compelling arguments for comprehensive sexuality education was made by a member of our youth program, a proud Pentecostal Christian from rural Mississippi. In a meeting with her Member of Congress, she explained that there was no sex education in her high school and a lot of girls in her class got “knocked up.” They did not graduate from high school. They did not marry. Their futures were compromised. But the impact of these unintended pregnancies goes well beyond the lives of these young women and their children. They contribute to the economic depression of their communities.

### **Conclusion**

Let’s be real and make a real difference. We know that 95% of Americans will have sex before they marry; therefore programs need to teach about abstinence and also about contraception, relationships and disease prevention. We must empower youth with the knowledge to make responsible decisions.

We believe that being of faith means being engaged in the world. And like it or not, the facts are clear: more than 80 percent of the 750,000 teen pregnancies each year are unintended and 25 percent of American teens contract an STD. We want our young people to be safe. For that to happen, they must be informed by comprehensive sex education. Offering them anything less is irresponsible and dangerous.



*Written Testimony of James Lacy, Past President, on behalf of Rotary International,  
Ph: 931-526-9726; [jim.lacy@rotary.org](mailto:jim.lacy@rotary.org) 27 April 2009*

Chairman Obey, Representative Tiahrt, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The effort to eradicate polio stands as an unprecedented model of cooperation among national governments, civil society and UN agencies which have worked together over many years to achieve a global public good. Longstanding collaboration has enabled us to overcome tremendous challenges: war, natural disasters, and lack of infrastructure among them, so that we are currently within reach of shared victory over polio. What have we learned? Polio eradication strategies work even in the most challenging environments and under the most trying circumstances.

#### **PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO**

I would like to take this opportunity to thank you, Chairman Obey, Representative Walsh, and members of the Subcommittee for your tremendous commitment to this effort. Thanks to your leadership in appropriating funds, progress toward a polio-free world continues.

- Only 4 countries are still polio-endemic – the lowest number in history: Nigeria, India, Pakistan and Afghanistan. And in these countries, polio circulates in very limited geographic areas.
- The number of polio cases has fallen from an estimated 350,000 in 1988 to 1,652 in 2008 – a more than 99% decline in reported cases.
- Of more than 100 wild poliovirus importation events during the period 2004-08 resulting in outbreaks in 26 countries, all but 11 have been stopped.
- New tools (eg monovalent vaccines, new diagnostic procedures) and tailored tactics for each country have been developed and fully incorporated into the intensified eradication effort.
- Policies to minimize the risks and consequences of the international spread of wild poliovirus are now in place.

Prospects for polio eradication are bright, but significant challenges remain. For example, operational challenges in reaching every child in the four endemic countries range from issues related to campaign quality, security, and funding. In addition, the need to deal with outbreak response activities in countries such as the Democratic Republic of Congo, Angola, Chad and Sudan are tragic and costly reminders that no child is safe until polio has been eradicated everywhere.

Continued political commitment is essential in all polio-affected countries. It is noteworthy that India, Nigeria and Pakistan have not relied solely upon international support, but have invested significant human and financial resources in their own polio eradication activities. There has been a surge in political commitment to polio eradication in the remaining polio endemic countries, highlights of which include the following:

- In February of this year, Nigeria's council of 36 state governors met and addressed the subject of polio eradication as a group *for the first time*. As a result of this extraordinary meeting, they signed the *Abuja Commitments to Polio Eradication*, in which they outlined steps they would take to ensure the achievement of polio eradication within their states and Nigeria as a whole. We can now work to hold the governors accountable to the commitments they made.

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- Ibrahim Shekarau, Governor of the State of Kano, northern Nigeria, the state which suspended polio campaigns in 2003 and which has been the epicenter of wild polio in Africa, now declares his full support for polio immunization and has publicly immunized his own daughter to visibly demonstrate his support.
- In late February, Pakistan's Prime Minister, Yusuf Raza Gillani, launched the "Prime Minister's Initiative for Polio Eradication in Pakistan" with a goal of freeing Pakistan from polio by the end of the year. The initiative involves several ministries and NGOs.
- In Afghanistan, President Hamid Karzai publicly launched the National Immunization Days in March and reiterated his strong commitment to work to protect Afghani children from polio – even those in conflict affected areas. It is noteworthy that President Karzai convened and personally oversees an interministerial group focused on polio which reports directly to him on a monthly basis so that he is continuously aware of the progress and challenges on this specific issue.
- In March, Health Ministers from member states of the Organization of the Islamic Conference met and adopted a strong statement of support for polio eradication efforts in OIC member states as part of their Resolution on Communicable Diseases. Three of the four remaining endemic countries are OIC member states (Afghanistan, Nigeria and Pakistan). Perhaps most significant among their recommendations, the OIC health ministers urged initiation of an OIC Polio Eradication Program, with the OIC Secretary General to take the lead, in collaboration with the Global Polio Eradication Initiative to assist in the process of eradication of Polio from the remaining OIC Member States. They also urged a joint OIC Secretariat and Islamic Development Bank mission to the three polio endemic OIC Member States to explore ways of direct assistance for polio eradication efforts in those states.

Those who are in a position to influence polio eradication in the remaining strongholds are taking decisive action to overcome the remaining obstacles.

The Department of Health and Human Services and the U.S. State Department have also been instrumental in promoting global polio eradication efforts at various international forums, in engaging with other donor countries to secure additional resources, and in helping deal with challenges in polio-affected countries.

The ongoing support of donor countries is essential to assure the necessary human and financial resources are made available to polio-endemic countries to take advantage of the window of opportunity to forever rid the world of polio. Access to children is needed, particularly in conflict-affected areas such as Afghanistan and its shared border with Pakistan. Polio-free countries must maintain high levels of routine polio immunization and surveillance. The continued leadership of the United States is essential to ensure we meet these challenges.

#### **THE ROLE OF ROTARY INTERNATIONAL**

Since 1985, Rotary International, a global association of more than 30,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in more than 200 countries, has been committed to battling this crippling disease. In the United States today there are more than 7,700 Rotary clubs with over 375,000 members. All of our clubs work to promote humanitarian service, high ethical standards in all vocations, and international understanding.

*Written Testimony of James Lacy, Past President, on behalf of Rotary International,  
Ph: 931-526-9726; [jim.lacy@rotary.org](mailto:jim.lacy@rotary.org) 27 April 2009*

Rotary International stands hand-in-hand with the United States Government and governments around the world to fight polio through local volunteer support of National Immunization Days, raising awareness about polio eradication, and providing financial support for the initiative.

Rotarians have reaffirmed their own commitment to achieve polio eradication and are currently in the midst of their third fundraising campaign, "Rotary's US\$200 Million Challenge," in response to an extraordinary challenge grant of US\$355 million global for polio eradication from the Bill & Melinda Gates Foundation. By the time the world is certified polio free, Rotary's contribution to global polio eradication will exceed US\$1.2 billion – second only to that of the United States Government. These funds have been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training and social mobilization in 122 countries. More importantly, tens of thousands of Rotarians have been mobilized to work together with their national ministries of health, UNICEF and WHO, and with health providers at the grassroots level in thousands of communities. In the United States, hundreds of Rotarians have been inspired to travel at their own expense to assist their fellow Rotarians in polio-affected countries in Africa and Asia during National Immunization Days.

In addition to providing financial support, Rotarians in other donor countries are working to ensure that those countries, particularly G8 member states, continue their vital financial support. Meanwhile, our Rotarian leaders in the remaining polio-affected countries work to ensure political commitment from the community level all the way to the head of state level. We are doing our best to ensure that we finish the job into which so much has been invested.

Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, the Task Force for Child Survival and Development, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in expressing appreciation to you for your staunch support of the Global Polio Eradication Initiative.

#### **THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's support of CDC's polio eradication activities. The investment in this global effort has helped to make the United States the leader among donor nations in the drive to eradicate this crippling disease. Due to Congress's unwavering support, in 2009 CDC is able to:

- Support the international assignment of more than 350 long- and short-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies, and 15 technical staff on direct assignment to WHO and UNICEF to assist polio-endemic countries.
- Provide \$42.5 million to UNICEF for approximately 279 million doses of polio vaccine and \$9 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.

*Written Testimony of James Lacy, Past President, on behalf of Rotary International,  
Ph: 931-526-9726; [jim.lacy@rotary.org](mailto:jim.lacy@rotary.org) 27 April 2009*

- Provide more than \$25 million to WHO for surveillance, technical staff and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance is critical to determine where polio cases continue to occur. Effective surveillance can save resources by eliminating the need for extensive immunization campaigns if it is determined that polio circulation is limited to a specific locale.
- Train virologists from all over the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.
- Provide the largest volume of both operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.
- Serve as the primary technical support agency to WHO on scientific and programmatic research regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

#### **BENEFITS OF POLIO ERADICATION**

Since 1988, over 5 million people who would otherwise have been paralyzed will be walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to investigate cases of acute flaccid paralysis and manage massive immunization programs. Cold chain, transport and communications systems for immunization have been strengthened.

Increased political and financial support for childhood immunization has many documented long-term benefits. Polio eradication is helping countries to develop public health and disease surveillance systems useful in the control of other vaccine-preventable infectious diseases. Already all 47 countries of the Americas are free of indigenous measles, due in part to improvements in the public health infrastructure implemented during the war on polio. The disease surveillance system--the network of 145 laboratories and trained personnel established during the Polio Eradication Initiative--is now being used to track measles, rubella, yellow fever, meningitis, and other deadly infectious diseases. Most recently, polio health workers have been trained to recognize symptoms of Avian Influenza in order to support surveillance and potential outbreak response activities for this emerging public health threat. The AFP surveillance system and global laboratory network that supports it will continue to support the surveillance of other diseases long after polio has been eradicated.

NIDs for polio have been used as an opportunity to give children essential vitamin A, which, like polio, is administered orally, saving the lives of at least 1.25 million children since 1998. The campaign to eliminate polio from communities has led to an increased public awareness of the benefits of immunization, creating a "culture of immunization" and resulting in increased usage of primary health care and higher immunization rates for other vaccines. It has improved public health communications and taught nations important lessons about vaccine storage and

Polio eradication is a cost-effective public health investment, as its benefits accrue forever. On the other hand, more than 10 million children will be paralyzed in the next 40 years if the world fails to capitalize on the more than \$6 billion already invested in polio eradication.

For Fiscal Year 2010, we respectfully request that you include \$102 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention. The funds we are seeking will allow CDC to continue intense supplementary immunization activities in Asia and to improve the quality of immunization campaigns in Africa to interrupt transmission of polio in these regions as quickly as possible. These funds will also help maintain certification standard surveillance. This will ensure that we protect the substantial investment we have made to protect the children of the world from this crippling disease by supporting the necessary eradication activities to eliminate polio in its final strongholds—in South Asia and sub-Saharan Africa.

Endemic nations are also providing funds to support polio eradication activities. It is noteworthy that India has provided US\$692 million in funding for polio eradication activities there since 2003 and Nigeria provided approximately US\$26 million, and Pakistan has provided US\$37 million.

## Ryan White Medical Providers Coalition

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### U.S. House Appropriations Labor, Health and Human Services Subcommittee

Kathleen Clanon, MD

Chair, Ryan White Medical Providers Coalition

Tri-City Health Center: HIVACCESS, Oakland, CA

kclanon@jba-cht.com

March 30, 2009

Dear Chairman and Ranking Member,

I am Dr. Kathleen Clanon, an HIV physician and director of the Tri-City Health Center's HIVACCESS program in Oakland, California. I am submitting public testimony on behalf of the Ryan White Medical Providers Coalition (RWMPc). I appreciate the opportunity to discuss the important HIV/AIDS care conducted at Ryan White Part C funded programs around the country and to request a dramatic increase in funds. **Specifically, we recommend a \$68.4 million increase for Part C for FY 10 resulting in a total appropriation of \$270,254,000.**

Our coalition was formed in 2006 to be a voice for medical providers across the nation delivering quality care to their patients through Part C of the Ryan White program. We represent every kind of program from small and rural to large urban sites in every region in the country. Our membership has rapidly increased as word spread that an advocacy group was forming to speak on behalf of the needs of Part C programs.

Ryan White Part C funds comprehensive HIV care and treatment—the services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. We speak for those who often cannot speak for themselves and we advocate for a full range of primary care services for this unique population. Sufficient funding for Part C is essential for the work that we do in service of those living with HIV/AIDS.

While the patient load in our programs is rising in number, funding for Part C has effectively decreased. At the same time, we expect a continued increase in patients due to higher diagnosis rates and declining insurance coverage. The CDC reports that the number of HIV/AIDS cases increased by 15 percent from 2004 to 2007 in 34 states.<sup>1</sup> Our patients struggle in times of plenty; during this economic downturn they will rely on our comprehensive services more than ever. An increase in funding is critical to ensure that we are able to sustain and improve our current staffing levels, which is important to ensure access to health care for our patients, as well as, to provide security to our community. Part C of the Ryan White program has been under-funded for years, but new pressures are creating a crisis in our community. The HIV medical clinics funded

<sup>1</sup> Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2007. Vol. 19. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2009:5. [www.cdc.gov/hiv/topics/surveillance/resources/reports/](http://www.cdc.gov/hiv/topics/surveillance/resources/reports/).

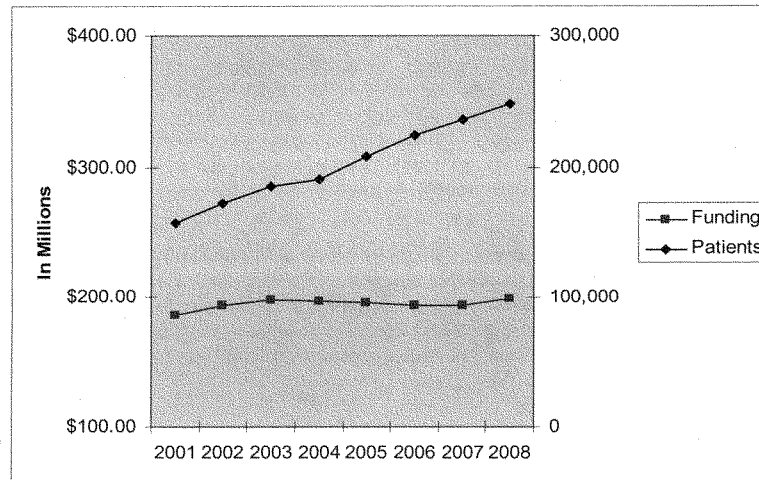
through Part C have been in dire of increased funding for years. An infusion of new funding would offer much needed assistance. Years of near flat funding, combined with large increases in the patient population, are negatively impacting the ability of Part C providers to serve their patients.

With the rapid cost increases in all aspects of health care delivery, despite small funding increases programs are still operating at a funding deficit because we are serving more patients than ever. In 2008, Part C programs will treat an estimated 248,070 – a dramatic 30% increase in less than 10 years. Our clinics are laying off staff, discontinuing critical services such as laboratory monitoring, creating waitlists, and operating on a 4-day work week just to get by. All of this at a time when the new data reporting requirements resulting from the 2006 reauthorization of Ryan White are requiring even more staff and administrative time than the 10% allocation permitted.

Frankly, we can do better than this and the HIV/AIDS population served through Part C deserves more support. I have included the following graph in my testimony to demonstrate the growing disparity between funding for Part C and our patient population. I call the gap between funding and patients the “Triangle of Misery” because it represents the thousands of patients who deserve more than we can offer them and the Part C programs around the nation who are struggling to serve them with rapidly shrinking resources.

#### THE TRIANGLE OF MISERY

**2001 to 2008: Part C Caseloads Increased 57%; Funding Increased 7 %**



The purpose of my testimony is to urge you to respond to this crisis and ask that you commit to doubling funding for Ryan White Part C programs by Fiscal Year 2012. Through a careful process that determined the actual cost of our care for our patients, the Ryan White Medical Providers Coalition worked collaboratively with the CAEAR Coalition and the American Academy of HIV Medicine to calculate the

funding demands for Ryan White Part C. We unanimously agreed that a Federal appropriation of \$407,300,078 is needed for Part C.

These are challenging fiscal times, and we recognize the multiple fiscal constraints you face as you determine how to allocate limited Federal dollars. That is why we are not asking for \$407.3 million for Ryan White Part C for FY 2010. Rather, we join with our partners in asking you to commit to doubling our funding by FY 2012. Such an agreement would result in an increase of \$68.4 million for Part C for each year: FY 10, FY 11, and FY 12. We believe this is a reasonable approach to meeting the needs of HIV/AIDS patients served by Part C around the country.

It is important for you to understand how we developed our request number. It is based on the following calculations:

- We assumed that 1,381,418 will be the number of people living with HIV/AIDS in 2012 based on the Centers for Disease Control and Prevention, New Estimates of HIV Prevalence, 2006. The estimate equals the CDC's 2006 estimated cases multiplied by their annual estimated prevalence increases for the years 2007-2012.
- Using data from the HRSA HIV/AIDS Bureau we estimated that 248,070 uninsured people living with HIV/AIDS were served by Part C programs in 2008.
- Using data from a report by Julie Gerberding, MD, MPH and Elizabeth Duke, PhD to the Honorable Henry Waxman (<http://oversight.house.gov/story.asp?ID1675>) we estimated that 168,688 PLWHA who were underinsured were served by Part C programs in 2008.
- We estimate the cost of care per patient at \$3,501 per year. (Gilman, BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care. 2008;20:1050-6.)
- We calculated the cost of providing care to uninsured Part C patients to be \$277,916,382 per year (79,382 patients x \$3,501 cost of care).
- We calculated the costs of providing care to underinsured Part C patients to be \$129,383,696 per year (168,688 patients x \$767 cost of care). The cost of care for underinsured patients is a conservative estimate based on Institute of Medicine figures.
- The total cost of care for all Part C patients will be \$407,300,078 in FY 2012.

Our data demonstrate the undeniable. Our patient load is increasing as is the cost of their care. A substantial Federal investment is necessary to support Part C sites around the country in their efforts to provide the comprehensive care that we know HIV/AIDS patients deserve and from which both they and our communities benefit.

I thank you for your attention to our request and urge you to commit to doubling the funding for Ryan White Part C in three years. **We request a \$68.4 million increase for Part C for FY 10 resulting in a total appropriation of \$270,254,000.** By working together, we are hopeful that in FY 2012 the full appropriation for Ryan White Part C will be \$407,300,078.

Thank you.





**STATEMENT OF  
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ON BEHALF OF  
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**ON BEHALF OF THE  
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300 ROSEWOOD DRIVE SUITE 105  
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**ON**

**FISCAL YEAR 2010 APPROPRIATIONS FOR THE  
DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**SUBMITTED TO THE  
HOUSE APPROPRIATIONS COMMITTEE; SUBCOMMITTEE ON LABOR, HEALTH  
AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES**

**MAY 1, 2009**

**Statement of Cynthia Cervantes  
Huntington Park, California  
Scleroderma Foundation**

Mr. Chairman, I am Cynthia Cervantes, I am 12 and in the ninth grade. I live in Southern California and in October 2006 I was diagnosed with scleroderma. Scleroderma means "hard skin" which is literally what scleroderma does and, in my case, also causes my internal organs to stiffen and contract. This is called diffuse scleroderma. It is a relatively rare disorder effecting only about 300,000 Americans.

About 2 years ago I began to experience sudden episodes of weakness, my body would ache and my vision was worsening, some days it was so bad I could barely get myself out of bed. I was taken to see a doctor after my feet became so swollen that calcium began to ooze out. It took the doctors (period of time) to figure out exactly what was wrong with me, because of how rare scleroderma is.

There is no known cause for scleroderma, which affects three times as many women as men. Generally, women are diagnosed between the ages of 25 and 45, but some kids, like me, are affected earlier in life. There is no cure for scleroderma, but it is often treated with skin softening agents, anti-inflammatory medication, and exposure to heat. Sometimes a feeding tube must be used with a scleroderma patient because their internal organs contract to a point where they have extreme difficulty digesting food.

The Scleroderma Foundation has been very helpful to me and my family. They have provided us with materials to educate my teachers and others about my disease. Also, the support groups the foundation helps organize are very helpful because they help show me that I can live a normal, healthy life, and how to approach those who are curious about why I wear gloves, even in hot weather. It really means a lot to me to be able to interact with other people in the same situation as me because it helps me feel less alone.

Mr. Chairman, because the causes of scleroderma are currently unknown and the disease is so rare, and we have a great deal to learn about it in order to be able to effectively treat it. I would like to ask you to please significantly increase funding for the National Institute of Health so treatments can be found for other people like me who suffer from scleroderma. It would also be helpful to start a program at the Centers for Disease Control and Prevention to educate the public and physicians about scleroderma.

**OVERVIEW OF THE SCLERODERMA FOUNDATION AND SCLERODERMA**

**SCLERODERMA FOUNDATION**

The Scleroderma Foundation is a nonprofit organization based in Danvers, MA with a three-fold mission of support, education, and research. The Foundation has 21 chapters nationwide and over 175 support groups.

The Scleroderma Foundation was established on January 1, 1998 through a merger between two organizations, one on the west coast and one on the east coast, which can trace their beginnings

back to the early 1970s. The Foundation's mission is to provide support for people living with scleroderma and their families through programs such as peer counseling, doctor referrals, and educational information, along with a toll-free telephone helpline for patients and a quarterly magazine, *The Scleroderma Voice*.

The Foundation also provides education about the disease to patients, families, the medical community, and the general public through a variety of awareness programs at both the local and national levels. Over \$1 million in peer-reviewed research grants are awarded annually to institutes and universities to stimulate progress in the search for a cause and cure for scleroderma. Building awareness of the disease to patients, families, the medical community and the general public to not only generate more funding for medical research, but foster a greater understanding of the complications faced by people living with the disease is a further major focus.

Among the many programs arranged by the Foundation is the Annual Patient Education Conference held each summer. The conference brings together an average of 500 attendees and experts for a wide range of workshops on such topics as the latest research initiatives, coping and disease management skills, caregiver support, and exercise programs.

#### **SCLERODERMA OVERVIEW**

Scleroderma is an autoimmune disease which means that it is a condition in which the body's immune system attacks its own tissues. In autoimmune disorders, this ability to distinguish foreign from self is compromised. As immune cells attack the body's own tissue, inflammation and damage result. Scleroderma (the name means "hard skin") can vary a great deal in terms of severity. For some, it is a mild condition; for others it can be life threatening. Although there are medications to slow down disease progression and help with symptoms, there is as yet no cure for scleroderma.

#### **WHO GETS SCLERODERMA?**

There are many clues that define susceptibility to develop scleroderma. A genetic basis for the disease has been suggested by the fact that it is more common among patients whose family members have other autoimmune diseases (such as lupus). In rare cases, scleroderma runs in families, although for the vast majority of patients there is no other family member affected. Some Native Americans and African Americans get worse scleroderma disease than Caucasians.

Women are more likely to get scleroderma. Environmental factors may trigger the disease in the susceptible host. Localized scleroderma is more common in children, whereas scleroderma is more common in adults. However, both can occur at any age.

There are an estimated 300,000 people in the United States who have scleroderma, about one third of whom have the systemic form of scleroderma. Diagnosis is difficult and there may be many misdiagnosed or undiagnosed cases as well.

Scleroderma can develop and is found in every age group from infants to the elderly, but its onset is most frequent between the ages of 25 to 55. There are many exceptions to the rules in scleroderma, perhaps more so than in other diseases. Each case is different.

### CAUSES OF SCLERODERMA

The cause is unknown. However, we do understand a great deal about the biological processes involved. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (which is overproduction of collagen) and immune system dysfunction, or autoimmunity.

### RESEARCH

Research suggests that the susceptible host for scleroderma is someone with a genetic predisposition to injury from some external agent, such as a viral or bacterial infection or a substance in the diet or environment. In localized scleroderma, the resulting damage is confined to the skin. In systemic sclerosis, the process causes injury to blood vessels, or indirectly perturbs the blood vessels by activating the immune system.

Research continues to assemble the pieces of the scleroderma puzzle to identify the susceptibility genes, to find the external trigger and cellular proteins driving fibrosis, and to interrupt the networks that perpetuate the disease.

### TYPES OF SCLERODERMA

There are two main forms of scleroderma: systemic (systemic sclerosis, SSc) that usually affects the internal organs or internal systems of the body as well as the skin, and localized that affects a local area of skin either in patches (morphea) or in a line down an arm or leg (linear scleroderma), or as a line down the forehead (scleroderma en coup de sabre). It is very unusual for localized scleroderma to develop into the systemic form.

#### Systemic Sclerosis (SSc)

There are two major types of systemic sclerosis or SSc: limited cutaneous SSc and diffuse cutaneous SSc. In limited SSc, skin thickening only involves the hands and forearms, lower legs and feet. In diffuse cutaneous disease, the hands, forearms, the upper arms, thighs, or trunk are affected.

The face can be affected in both forms. The importance of making the distinction between limited and diffuse disease is that the extent of skin involvement tends to reflect the degree of internal organ involvement.

Several clinical features occur in both limited and diffuse cutaneous SSc. Raynaud's phenomenon occurs in both. Raynaud's phenomenon is a condition in which the fingers turn pale or blue upon cold exposure, and then become ruddy or red upon warming up. These episodes are caused by a spasm of the small blood vessels in the fingers. As time goes on, these small blood vessels become damaged to the point that they are totally blocked. This can lead to ulcerations of the fingertips.

People with the diffuse form of SSc are at risk of developing pulmonary fibrosis (scar tissue in the lungs that interferes with breathing, also called interstitial lung disease), kidney disease, and bowel disease.

The risk of extensive gut involvement, with slowing of the movement or motility of the stomach and bowel, is higher in those with diffuse rather than limited SSc. Symptoms include feeling bloated after eating, diarrhea or alternating diarrhea and constipation.

Calcinosis refers to the presence of calcium deposits in, or just under, the skin. This takes the form of firm nodules or lumps that tend to occur on the fingers or forearms, but can occur anywhere on the body. These calcium deposits can sometimes break out to the skin surface and drain whitish material (described as having the consistency of toothpaste).

Pulmonary Hypertension (PH) is high blood pressure in the blood vessels of the lungs. It is totally independent of the usual blood pressure that is taken in the arm. This tends to develop in patients with limited SSc after several years of disease. The most common symptom is shortness of breath on exertion. However, several tests need to be done to determine if PH is the real culprit. There are now many medications to treat PH.

#### **Localized Scleroderma**

##### Morphea

Morphea consists of patches of thickened skin that can vary from half an inch to six inches or more in diameter. The patches can be lighter or darker than the surrounding skin and thus tend to stand out. Morphea, as well as the other forms of localized scleroderma, does not affect internal organs.

##### Linear scleroderma

Linear scleroderma consists of a line of thickened skin down an arm or leg on one side. The fatty layer under the skin can be lost, so the affected limb is thinner than the other one. In growing children, the affected arm or leg can be shorter than the other.

##### Scleroderma en coup de sabre

Scleroderma en coup de sabre is a form of linear scleroderma in which the line of skin thickening occurs on the forehead or elsewhere on the face. In growing children, both linear scleroderma and en coup de sabre can result in distortion of the growing limb or lack of symmetry of both sides of the face.

### **FY10 APPROPRIATIONS RECOMMENDATIONS**

- A 7% overall increase for the National Institutes of Health (NIH).
- A 7% increase for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the NIH.
  - A Committee recommendation encouraging NIAMS to support a State of the Science Conference on Scleroderma in FY10.
- Committee recommendation encouraging the Centers for Disease Control and Prevention to partner with the Scleroderma Foundation to promoting increased awareness of scleroderma among the general public and health care providers.

**Society for Neuroscience  
House Appropriations Subcommittee on Labor, Health and Human Services, Education  
and Related Agencies  
FY 2010 National Institutes of Health Appropriations**

**Submitted by Thomas J. Carew, Ph.D.  
President, Society for Neuroscience  
University of California, Irvine  
(949) 824-6114, tcarew@uci.edu**

**Introduction**

Mr. Chairman and members of the subcommittee, I am Thomas J. Carew. I am the Donald Bren Professor and Chair of the Neurobiology and Behavior in the School of Biological Sciences at the University of California, Irvine, and President of the Society for Neuroscience (SfN).

Mr. Chairman, on behalf of the more than 38,000 members of the Society and myself, I would like to thank you and the members of this subcommittee for your past support, particularly the recent funds provided for the National Institutes of Health (NIH) in the American Recovery and Reinvestment Act (ARRA). This investment illustrates the confidence of Congress that research funded by NIH will continue to provide significant economic and health care returns to the American taxpayer.

I respectfully request that Congress provide for a consistent and reliable long term investment in NIH and in particular the field of neuroscience. Neuroscience includes research aimed at understanding the brain and the nervous system to better treat and prevent the thousands of diseases of the brain and nervous system that afflict millions of Americans.

**Fiscal Year 2010 Budget Request**

SfN is very grateful for the \$10.4 billion in the ARRA for NIH. Already, the scientific community is hard at work pushing these dollars into high quality research while creating and preserving jobs. This investment will spur growth to help stimulate the national and local economies in these extraordinary times. After six years of budget increases that failed to keep pace with biomedical research inflation, resulting in the loss of 17 percent of NIH's purchasing power, the research funding in the ARRA is clear recognition of the role biomedical research plays in supporting our economy and laying the groundwork for future investments.

To ensure that the nation seizes on the scientific and economic momentum being driven by these funds and to maintain a robust research agenda, **we respectfully request an increase of 10 percent over the FY2009 level, providing a total budget for NIH of \$33.35 billion for FY2010** with a goal of reaching \$40 billion as soon as possible. By preventing NIH funding from dropping off a dramatic cliff at the end of FY 2010, this recommendation is a responsible way to ensure biomedical research continues to help drive the transformation of science, medicine and health. It also helps achieve the Administration's commitment to return science to its rightful place by doubling its funding over the next 10 years. At a time of abundant scientific

opportunities, global economic competition and unprecedented health challenges, it is imperative that NIH has the resources necessary to generate significant progress.

#### **What is the Society for Neuroscience?**

The Society for Neuroscience is a nonprofit membership organization of basic scientists and physicians who study the brain and nervous system. When the Society was first formed 40 years ago, it had less than 500 members. Today, SfN is the world's largest organization of scientists devoted to the study of the brain. Our member neuroscientists conduct research on the human brain to learn about its normal functions. They are also interested in learning how the nervous system develops, matures and maintains itself through life and how to improve treatment and prevention methods for psychiatric and neurological disorders.

Neuroscience is a unified field that combines biology, chemistry and physics with studies of structure, physiology and behavior, including cognitive and emotional functions in humans. Neuroscience research includes genes and other molecules that are the basis for the nervous system, individual neurons and neuron elements that make up systems and behavior.

#### **NIH-Funded Research Leads to Advances in Health**

NIH support has enabled neuroscientists to make significant progress in diagnosing and treating neurological disorders. Today, scientists have a much better understanding of how the brain functions, a few examples of which are illustrated in the below examples culled from SfN's *Brain Research Success Stories* and *Brain Briefings*. This neuroscience research and the possible health advances would not have been possible without constant and stable NIH support.

*Post-Traumatic Stress Disorder* –With a new generation of U.S. soldiers coming home after prolonged exposure to combat-related stress or trauma, understanding and treating PTSD has taken on an increased sense of urgency. One of the major unanswered questions about PTSD involves susceptibility. Not everybody who experiences psychological and/or physical trauma develops the disorder. Patients with PTSD have heightened levels of norepinephrine, a chemical involved in arousal and stress. High levels of this chemical strengthen the emotional reactions of the amygdala, a brain region involved in the fear response, while weakening the rational functions of the prefrontal cortex, which normally allows us to suppress troubling memories and thoughts. Research shows that a drug called D-cycloserine, when used in combination with behavioral therapy, appears to enhance the fear extinction process. Another drug, the beta-blocker propranolol, has shown some evidence of being able to prevent the development of certain PTSD features when administered within hours of a traumatic experience. Traumatic stress cannot always be avoided. But research is pointing to new and more effective ways of helping individuals successfully prevent or break the disabling cycle of recurring PTSD symptoms.

*Memory Impairment* – Another area of exciting discoveries, and one where I have conducted research, is memory impairment. While the battle against memory loss has gained significant ground in recent years, the advances are still not enough for those affected by memory impairment. NIH-funded studies found that a brain cell component termed the AMPA receptor aids the brain's memory system. A compound that targets the AMPA receptor has been shown to produce benefits in animals and is now being tested in patients with Alzheimer's disease.

Another study determined that activity at another brain cell component, the GABA B receptor, can suppress the memory process. Early findings indicate that a compound that blocks the receptor's activity improves the memory of patients with mild cognitive impairment. The far-ranging payoffs from a greater understanding of memory loss that affects many older Americans and the resulting development of new medications can only be attained with a continued and reliable investment in research.

*Traumatic Brain Injury* – Traumatic brain injury (TBI) is a complex injury with a broad spectrum of symptoms and disabilities, and the impact on a person and his or her family can be devastating. While MRI and CAT scans are often normal, the individual has cognitive problems such as headache, difficulty thinking, memory problems, attention deficit, mood swings and frustration. Research funded by NIH is pointing to new strategies that could take direct action against the injury and create much greater improvements in patient care. Techniques that hold promise include the use of transplanted neural stem cells that could potentially provide dramatic improvements in treating TBI. Scientists long imagined that, in the same way new bricks can repair a crumbling bridge, transplants of fresh cells might help rebuild damaged brain cell circuits that occur from a head injury. In addition, these cells might also be used to deliver small molecules that can protect the brain from further damage. Recent animal research, sponsored in part by NIH, provides evidence that cell transplant strategies may promote the repair of an injured brain and help restore lost abilities. Still, following TBI, the environment within which these transplanted cells must survive and grow is fundamentally changed. With continued support from NIH, researchers will have an opportunity overcome some of the limitations of current treatments and help improve the lives of thousands of people.

#### **Basic Research – Fundamental Science**

Robust and reliable investment in NIH is crucial to improve American health care *and* strengthen our economy. Basic research advances scientific knowledge and medical innovation by expanding the understanding of the structure and function of molecules, genes, cells, systems and complex behaviors.

*Vision and Gene Therapy* - Vision loss and eye disease affect 3.6 million Americans and cost the United States \$68 billion each year. However, advances in vision research are helping to combat some types of eye disease. An unexpected finding decades ago — the crucial role of vitamin A in the visual system — and the genetic revolution that began with the decoding of the human genome have combined to create one of the first success stories for gene therapy and hope for vision restoration for people with Leber congenital amaurosis (LCA), a disorder once believed to be permanent. LCA, the most common cause of congenital vision loss in children, becomes more severe through adolescence, leading to complete blindness in adulthood. Researchers at the National Eye Institute discovered that a mutation of the RPE65 gene caused a form of LCA called LCA2 and in 2007, using both mice and dog animal models, developed a new form of gene therapy that improved the animals' abilities to respond to light. Subsequently, in preliminary studies of young adults with LCA2, researchers reported that the gene therapy improved vision. After receiving treatment, two participants who had been unable to see a hand waving in front of them could see well enough to move around without help. One participant's vision improved so much that he was able to read small print with the help of a magnifying glass.



This exciting breakthrough was the result of basic research conducted 70 years ago and has significant implications for gene research and therapy beyond the eye.

*Plasticity and Alzheimer's Disease* – Researchers in the 1960s wanted to understand more about growth and repair in the adult brain and conducted a number of experiments with rodents to help illuminate these processes. They made an amazing and unexpected discovery: newly created cells that later became neurons, or brain cells. This process, called neurogenesis, is just one example of how “plastic” or adaptable the brain is. With this knowledge, researchers are investigating how normal aging, as well as neurodegenerative diseases like Alzheimer’s disease, affect that adaptability, and how we can maintain healthy brain function as we age. Future research may one day allow scientists to capture the adult brain’s enormous capacity to adapt in order to help prevent, or perhaps even reverse, memory-robbing Alzheimer’s disease.

#### **The Pipeline of New Researchers**

SfN is very concerned about the impact of the stagnant budget on keeping young researchers in the training pipeline. In 1990, young researchers received 29 percent of R01 grants (the premier NIH research grant needed to establish a researcher’s credibility and independence), but by 2007, only 25 percent of such grants were awarded to young scientists. Additionally, the age of those receiving their first R01 has increased from 38 to 43.

Currently, science is balancing on a knife’s edge, threatened with losing a generation of extraordinary scientists struggling for independence and resources. With flat or falling funding, a remarkable cohort of young people has been imperiled, at least in part, because the scientific enterprise has not been structured to prepare for career holding patterns. SfN is tremendously hopeful that the increasing support for science will encourage this next generation of professionals to stay the course, and that the science community will make it a high priority to ensure they have a place at the table. However, there is only a year or so before young scientists become an endangered species. If they are lost now, society loses their advances 20 to 40 years from now. And if they go, it will take a long, long time to reconstitute laboratory groups when funds come back in place. Once lost, intellectual, scientific, and personal momentum is incredibly hard to regain. A renewed, sustained focus on support for science would provide an extraordinary opportunity to strengthen the scientific enterprise by supporting young scientists.

Additionally, we are concerned that the U.S. may soon no longer be the global source of the basic and translational science that fosters advances in medicine. Decreases in the scientific workforce could have an adverse effect on local and state economies as universities and research institutions are the largest employers in some communities. Projects conducted by these institutions contribute to the growth in biotechnology, pharmaceuticals, device and imaging manufacturing and other industries.

We owe it to the next generation of scientists to ensure that they have the opportunity to pursue their passion for research and discovery, which ultimately provides benefits for all Americans.

#### **Conclusion**

We urge Congress to support President Obama’s call to return science to its rightful place and double science funding over 10 years. Research funding is a proven pathway to better health and a stronger, high-tech, high-wage economy. Already, it has created new treatments to improve

health and quality of life. In particular, neuroscience has resulted in progress on PTSD and TBI affecting our troops, exciting discoveries in Alzheimer's and Parkinson's disease that will affect even more Americans as the nation ages, and amazing advances in restoring vision to individuals once thought to be permanently blind.

These exciting benefits to the nation's health care and the economy will not be fully realized if we do not seize the scientific momentum brought about by ARRA funds. Sfn's recommendation of at least a 10 percent increase, supported by many in the research and patient advocacy communities, ensures there is not a dramatic drop in research funding at the end of FY2010 and allows the world's pre-eminent medical research enterprise to accelerate the momentum of discovery to improve the health, quality of life, and economic well-being of millions of Americans.

Through the support of the Congress and the general public, NIH has become the world's leading medical research enterprise. Research funded by the NIH has created new treatments to improve our health and our quality of life. In the past 40 years, NIH funded research has successfully reduced the mortality and morbidity of once acute and lethal conditions by finding ways to improve treatment. Additional funding for NIH will make it possible to explore and understand the fundamental causes of disease at the earliest stages, and predict a disease before it develops.

The brain is the most complex living structure known in the universe. Neuroscience advances our understanding of the brain and nervous system by bringing together scientists of diverse backgrounds and encouraging translational research while applying new scientific knowledge to develop improved disease treatments and cures. We urge Congress to provide adequate federal funding to advance scientific understanding needed to improve the health of countless Americans.

Thank you for the opportunity to submit this testimony.

Sincerely,

Thomas J. Carew  
President, Society for Neuroscience  
Bren Professor and Chair  
Department of Neurobiology and Behavior  
University of California, Irvine



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**Public Record Testimony of the Society for Public Health Education**

Regarding FY 2010 Funding for Disease Prevention and Wellness Programs

Presented to the  
 United States House of Representatives Committee on Appropriations  
 Subcommittee on Labor, Health and Human Services, Education and Related  
 Agencies  
 May 1, 2009

The Society for Public Health Education (SOPHE) is a professional health education organization founded in 1950 to promote the health of all people by stimulating research on the theory and practice of health behavior; translating sound science into practice; and supporting high quality standards for professional preparation. SOPHE is the only professional organization devoted exclusively to public health education and health promotion. SOPHE members work daily to improve health outcomes and promote wellness in a variety of health settings, including schools, universities, health care organizations, corporations, voluntary health agencies and federal, state and local government. There are currently 20 SOPHE chapters covering 32 states across the country.

SOPHE's broad membership enables us to advocate and understand the need for increased resources to the most pressing public health issues. For the FY 2010 funding cycle SOPHE encourages the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to increase funding for public health programs that focus on preventing chronic disease and other illnesses; eliminating health disparities and promoting the coordinated school health model. In particular, SOPHE would like to request the following FY 2010 funding levels for Labor-HHS programs:

- **\$1.66 billion for the National Center for Chronic Disease Prevention and Health Promotion**
- **\$60 million for the CDC REACH (Racial and Ethnic Approaches to Community Health) program**
- **\$48.6 million for CDC DASH (Division of Adolescent and School Health)**
- **Restore funding to the National Center for Health Marketing to FY 2008 levels.**

SOPHE gratefully acknowledges the strong bipartisan support that the House Subcommittee on Labor, Health and Human Services and Education has provided to the Centers for Disease Control and Prevention (CDC) in recent years, including the funding dedicated to the Prevention and Wellness Fund in the American Recovery and Reinvestment Act of 2009. However, many community-based programs have yet to obtain funds from ARRA and until these funds are distributed they should not be considered for the FY 2010 funding cycle.

The field of health education, which is some 100 years old, uses sound science to plan, implement, and evaluate interventions that enable individuals, groups, and communities to achieve personal, environmental and social health. These interventions address both infectious and chronic diseases, as well as risk communication with the public. There is a robust, scientific evidence-base documenting not only that various health education interventions work but that they are also cost-effective. These principles serve as the basis for our support for many of the programs outlined below.

#### Preventing Chronic Disease

The data is clear - chronic diseases are the nation's leading causes of morbidity and mortality and account for 75% of every dollar spent on health care in the U.S. Collectively, they account for 70% of all deaths nationwide. Thus, it is highly likely that 3 of 4 persons living in the districts of the Labor-HHS Subcommittee members will likely develop a chronic condition requiring long-term and costly medical intervention in their lifetime. In 2008, heart disease & stroke were estimated to cost \$448 billion in medical expenditures and lost productivity. U.S. healthcare expenditures total nearly \$7,000 annually for every man, woman, and child, primarily for diagnosis and treatment of chronic diseases.

**SOPHE is requesting a FY 2010 funding level of \$1.66 billion for CDC's National Center for Chronic Disease Prevention and Health Promotion** in order to adequately address the cost of chronic disease care and prevent it from further burdening our nation's citizens. NCCDPHP is at the forefront of the nation's efforts to prevent and control chronic diseases. It was substantially cut in 2006, and then has essentially been level-funded and decreasing due to across the board rescissions – while chronic disease rates have continued to soar.

Studies have shown that by spending as little as \$10 per person on proven preventive interventions could save the country over \$16 billion in just five years. The public overwhelmingly supports increased funding for disease prevention and health promotion programs. Small investments now in community-led, innovative programs will help to increase our nation's productivity and performance in the global market while also decreasing rates of infant mortality, deaths due to cancer, cardiovascular disease, diabetes and HIV/AIDS, and also increase our immunization rates.

Chronic disease prevention programs, like those delivered by NCCDPHP are more needed than ever among our nation's youth. In the last 20 years, the percentage of overweight youth has more than doubled. Fifteen percent of children and adolescents are overweight and more than half of these children have at least one cardiovascular disease risk factor, such as elevated cholesterol or high blood pressure. Almost 80 percent of young people do not eat the recommended five servings of fruits and vegetables each day. Daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 percent in 2001. Patterns of poor nutrition, lack of physical activity, and other behaviors such as alcohol and tobacco use established during youth often continue into adulthood and contribute markedly to costly, chronic conditions.

CDC's Coordinated School Health Programs have been shown to be cost-effective in improving children's health, behavior, and their academic success. This funding builds bridges between state education and public health departments to coordinate health education, nutritious meals, physical education, counseling, health services, healthy school environments, health promotion of faculty, and parent and community involvement. Gallup polls show strong parental, teacher, and public support for school health education.

**SOPHE urges this subcommittee to support an appropriation of \$48.6 million in FY 2010 for CDC's Division of Adolescent and School Health, Coordinated School Health Programs.** This represents an increase of \$35 million for the School Health Program to expand the number of states and tribes funded from 23 to 51. Twenty-eight states and territories were approved for funding in the last funding cycle, but did not receive awards due to a lack of federal funds.

Chronic diseases account for the largest health gap among populations and increase health disparities among racial and ethnic minority groups. As the U.S. population becomes increasingly diverse, the nation's health status will be heavily influenced by the morbidity of racial and ethnic minority communities. African Americans, Alaskan Natives, American Indians, Asian Americans, Hispanic Americans, and Pacific Islanders are more likely than whites to have poor health and to die prematurely. African Americans have higher mortality rates for cardiovascular disease and stroke, and cancer of the lung, colon/rectum, breast, cervix, and prostate than Whites, American Indians/Alaska Natives, Asian/Pacific Islanders, and Hispanic Americans.

**SOPHE strongly urges an allocation of \$60 million for CDC's Racial and Ethnic Approaches to Community Health across the U.S. (REACH U.S.)** to eliminate health disparities among urban and rural communities in the areas of cardiovascular disease, immunizations, breast and cervical cancer screening and management, diabetes, HIV infections/AIDS, and infant mortality. In 2007, over 200 communities applied for REACH U.S. funding; however because of limited resources only 40 communities were funded.

Launched in 2007, REACH U.S. is the next evolution of REACH 2010 which was developed by HHS and CDC to find "out of the box" community-driven solutions to address health disparities. REACH U.S. is part of CDC's Healthy Communities Program and is unique because it works across public and private sectors to conduct community-based prevention research and demonstration projects that address social determinants of health. REACH U.S. programs are time-tested, community-led interventions that have proven success in decreasing health disparities among some of our nation's most needy communities. President Obama highlighted a need to address health disparities in his FY 2010 Budget Blueprint and with increased funding REACH U.S. programs stand ready to address his call to action.

Center for Health Marketing

As the Swine Flu epidemic sweeps across our nation, we have found more than ever we need to invest in our health communications resources. In the FY 2009 Labor-HHS bill, the National Center for Health Marketing was drastically cut in funding. **SOPHE urges the committee to restore the funding for the National Center for Health Marketing back to its FY 2008 level.** Not only does this Center serve in informing the public in times of emergency, but it also works to prepare our public health community to prevent instances such as the Swine Flu epidemic from turning into a public health disaster.

Ensuring Prevention is a Priority in Health Reform

The nation is at a critical juncture in disease prevention and health promotion as Congress works to reform our health care system. **SOPHE strongly encourages the inclusion of prevention and wellness programs as a cornerstone of any health reform effort.** Science-based programs in health education and health promotion that combine individual behavior change with community-led interventions, policies and practices are effective, thereby saving lives and reducing U.S. health care expenditures. If we fail to include prevention and wellness in health reform now, we will find that our health systems will continue to be burdened by the costs of caring for chronic and infectious diseases that could have been easily prevented.

We thank you for this opportunity to present our views to this Subcommittee. We look forward to working with you to improve the health and safety of all Americans.

Martha Nolan,  
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**Written Testimony By:**

**Phyllis Greenberger, MSW: President and CEO, Society for Women's Health Research  
 and Jeanne Becker, Ph.D.: Chair, Women's Health Research Coalition**

**Before the House Appropriations Subcommittee on Labor, Health and Human Services,  
 Education, and Other Related Agencies**

**May 1, 2009**

**Submitted for the Record**

On the behalf of the Society for Women's Health Research and the Women's Health Research Coalition, we are pleased to submit the following testimony in support of federal funding of biomedical research, and in particular women's health research.

The Society for Women's Health Research is the nation's only non-profit organization whose mission is to improve the health of all women through advocacy, research, and education. Founded in 1990, the Society brought to national attention the need for the appropriate inclusion of women in major medical research studies and the need for more information about conditions affecting women exclusively, disproportionately, or differently than men. The Society advocates increased funding for research on women's health; encourages the study of sex differences that may affect the prevention, diagnosis and treatment of disease; promotes the inclusion of women in medical research studies; and informs women, providers, policy makers and media about contemporary women's health issues. In 1999, the Women's Health Research Coalition was created by the Society as a grassroots advocacy effort consisting of scientists, researchers, and clinicians from across the country that are concerned and committed to improving women's health research.

The Society and Coalition are committed to advancing the health of women through the discovery of new and useful scientific knowledge. We believe that sustained funding for biomedical and women's health research programs conducted and supported across the federal agencies are absolutely essential if we are to meet the health needs of the population and advance the nation's research capability.

**National Institutes of Health**

Congressional investment and support for NIH continues to make the United States the world leader in biomedical research and has provided a direct and significant impact on women's health research and the careers of women scientists over the last decade. Great strides and advancements were made through the doubling of the NIH budget from \$13.7 billion in 1998 to \$27 billion in 2003, though the momentum driving new research in recent years was eroded under budgetary constraints. The 111<sup>th</sup> Congress saw the importance of increasing funds to NIH in the FY09 Omnibus bill providing the NIH with \$30.317 billion, \$937.5 million over FY08, (a 3.2% increase.) Thankfully, Congress also sought fit to include the NIH in the American Recovery and Reinvestment Act of 2009 [P.L. - 111-5] (ARRA) providing it with an infusion of



short term funding of \$10.4 billion. This funding will have and is having an enormous impact on research and research facilities throughout the United States, creating new jobs, new innovations and improved technologies.

Without a robust budget, NIH has shown that it is forced to reduce the number of grants it is able to fund. The number of new grants funded by NIH has dropped steadily since FY2003 and this trend must stop. This shrinking pool of available grants has a significant impact on scientists who depend upon NIH support to cover their salaries and laboratory expenses to conduct high quality biomedical research. Failure to obtain a grant results in reduced likelihood of achieving tenure. This means that new and less established researchers are forced to consider other careers, the end result being the loss of the critical workforce so desperately needed to sustain America's cutting edge in biomedical research.

In order to continue the momentum of scientific advancement and expedite the translation of research findings from the laboratory to the patients who depend on these advances for improved health and welfare, the Society proposes **a 10% increase over FY 09, and establishing a goal of reaching an annual appropriation of \$40 billion in the next 3 years.** In addition, we request that Congress strongly encourage the NIH to utilize ARRA funding as well as appropriated dollars to assure that women's health research receives resources sufficient to meet the health needs of all women. Further the Society recommends that NIH support the advances being discovered in sex-based biology research.

Scientists have long known of the anatomical differences between men and women, but only within the past decade have they begun to uncover significant biological and physiological differences. Sex-based biology, the study of biological and physiological differences between men and women, has revolutionized the way that the scientific community views the sexes. Sex differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, heart disease, immune dysfunction, mental health disorders, and many other illnesses. It is imperative that research addressing these important differences between males and females be supported and encouraged. Congress clearly recognizes these important sex differences and NIH should as well.

#### **Office of Research on Women's Health**

The NIH Office of Research on Women's Health (ORWH) has a fundamental role in coordinating women's health research at NIH, advising the NIH Director on matters relating to research on women's health and sex and gender research; strengthening and enhancing research related to diseases, disorders, and conditions that affect women; working to ensure that women are appropriately represented in research studies supported by NIH; and developing opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. ORWH is currently implementing recommendations from the NIH working Group on Women in Biomedical Careers to maximize the potential of women biomedical scientists and engineers in both the NIH and extramural community.

Two highly successful programs supported by ORWH that are critical to furthering the advancement of women's health research are Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR). These programs benefit the health of both women and men

through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment.

The BIRCWH program is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. It is expected that each scholar's BIRCWH experience will culminate in the development of an established independent researcher in women's health. The BIRCWH program has released four RFAs (1999, 2001, 2004, and 2006). Since 2000, 335 scholars have been trained (76% women) in the twenty-four centers resulting in over 1300 publications, 750 abstracts, 200 NIH grants and 85 awards from industry and institutional sources. Each BIRCWH receives approximately \$500,000 a year, most of which comes from the ORWH budget but is also supported by many NIH Institutes and Centers.

The SCOR program was developed by ORWH in 2002. SCORs are designed to increase the transfer of basic research findings into clinical practice by housing laboratory and clinical studies under one roof. The eleven SCOR programs are conducting interdisciplinary research focused on major medical problems affecting women and comparing gender differences to health and disease. Each SCOR works hard to transfer their basic research findings into the clinical practice setting. In 2007, 7 SCORS competed successfully for renewal and 4 new SCORS were added. In 2008, the 11 SCORs report publishing 113 journal articles, 144 abstracts, and 30 other publications. Each program costs approximately \$1 million per year and results in research that would not have taken place without this program.

Advancing Novel Science in Women's Health Research (ANSWHR) was created by ORWH in 2007 and funding starting in July 2008 to promote innovative new concepts and interdisciplinary research in women's health research and sex/gender differences. This program has had broad appeal and is evolving into an important scientific tool for both early-stage investigators and veteran researchers to test nascent scientific concepts relevant to women's health research and the study of sex and gender differences. Researchers can apply for support to promote innovative, interdisciplinary research to answer unresolved questions and expand the knowledge base in a host of areas relevant to women's health research. In FY 2009, 13 ICs have one or more applications that have been scientifically reviewed and are considered competitive for funding. These applications, and the FY 2008 awards, represent a wide range of scientific areas as well as junior investigators and experienced researchers. ANSWHR serves as a way for interested researchers to compete for funding that is expanding the scientific basis for women's health research and the study of sex and gender differences.

ORWH also has the Research Enhancement Awards Program (REAP) to support meritorious research on women's health that just missed the IC pay line and a Partnership with the National Library of medicine to identify overarching themes, specific health topics, and research initiatives into women's health.

ORWH, through successful collaboration with the NIH ICs provides research funding for: breast cancer pharmacogenomics, HPV vaccines, uterine leiomyoma, vulvodynia, irritable bowel syndrome, stroke, substance abuse, eating disorders including obesity, menopause, microbicides, chronic pain syndromes, autoimmune disorders, muscular skeletal disorders, and health disparities among many other issues.

Despite all of ORWH's advancements of women's health research and its innovative programs to advance women scientists, the office has seen its budget flat lined at \$40.9 million for FY 2008 and 2009 after having also received a cut of \$249,000 in FY06 and no additional funding in FY07. Flat funding is the same as receiving a decrease in budget and must not continue to happen. In order for ORWH's programs and research grants to thrive Congress must direct that NIH to continue its support of ORWH and **provide it with \$2 million dollar budget increase.**

#### **Department of Health and Human Services**

Under the Department of Health and Human Services (HHS) several agencies have federal offices on women's health, in addition to ORWH described above. Agencies with offices, advisors or coordinators for women's health or women's health research are HHS, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Quality and Research, the Indian Health Service, the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, and the Centers for Medicare and Medicaid Services. It is imperative that these offices are funded at levels adequate for them to perform their assigned missions. We ask that the Committee Report clarify that Congress supports the permanent existence of these various federal women's health offices and recommends that they are appropriately funded to ensure that their programs can continue and be strengthened in the coming fiscal year.

#### **HHS Office of Women's Health**

The HHS Office of Women's Health (OWH) is the government's champion and focal point for women's health issues. It works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. The OWH coordinates women's health efforts in HHS to eliminate disparities in health status and supports culturally sensitive educational programs that encourage women to take personal responsibility for their own health and wellness. OWH has a central role in communicating the appropriate messages to patients and health care providers, helping to move forward recent research discoveries. Without OWH's actions the task of translating research into practice would and will be only more difficult and delayed.

Over the years OWH has been active in various efforts such as: joining with the National Institutes of Health to launch the "The Heart Truth" campaign, a prevention and awareness campaign concerning heart disease and women; leading a series of Women's Heart Health Fairs nationwide; partnering with the Lupus Foundation of America and the Advertising Council to launch a new lupus public awareness campaign targeted toward young minority women of childbearing age who are at most risk for developing the disease to identify early warning signs.

OWH created a new training program "Body Works" for parents and caregivers designed to improve family eating and activity habits and is available in both English and Spanish. They collaborated with other organizations to lead a conference on "Charting New Frontiers in Rural Women's Health," as well as hosting the 3rd Minority Women's Health Summit to address the unique health issues many women of color experience. In addition, OWH has continued its efforts to improve the health of young women by providing information on their website to address eating disorders and HIV/AIDS prevention for adolescent girls, in conjunction with conducting their HIV/AIDS National Awareness Day. Further, OWH is leading efforts to improve breastfeeding information available to women of all cultures by offering multilingual websites and help-lines.

This year marks the 10<sup>th</sup> anniversary of the launch of the womenshealth.gov website and care center and National Women's Health Week. As part of the annual celebration, OWH is sponsoring many events with communities, businesses and other governmental and health organizations to educate women on how they can improve their physical and mental health. Further, this year OWH is celebrating the publication of *"The Healthy Women"* a book with wonderful health information and tips for women of all ages.

It is only through continued and increased funding that the OWH will be able to achieve its goals. While the budget for FY 2008 increased the OWH budget by \$2 million to a total of \$30 million, its budget was flat lined for FY 2009. This is, in essence, a decrease due to inflation. Considering the amount and impact of women's health programs from OWH, we urge Congress to provide an increase of **\$2 million** for the HHS OWH for FY 2010.

#### **Agency for Healthcare and Research Quality**

The Agency for Healthcare Research and Quality (AHRQ) is the lead public health service agency focused on health care quality, including coordination of all federal quality improvement efforts and health services research. AHRQ's work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of health care. This important information provided by AHRQ is brought to the attention of policymakers, health care providers, and consumers all of whom make a difference in the quality of health care women receive. Through AHRQ's research projects and findings, lives have been saved and underserved populations have been treated. For example, women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines, which have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks.

While AHRQ has made great strides in women's health research, its budget has been dismally funded for years though targeted funding increases in recent years for dedicated projects are moving AHRQ in the right direction. However, more core funding is needed to help AHRQ fulfill its mission. AHRQ's budget for FY09 was \$372 million. This must change for FY210. The Society recognizes that AHRQ received a dramatic boost under ARRA of \$400 million of dedicated stimulus funding for the comparative effectiveness project this amount does not add to AHRQ's base numbers. This Agency has been operating under a major shortfall for years. Decreased funding seriously jeopardizes the research and quality improvement programs that Congress mandates from AHRQ.

We recommend Congress fund AHRQ at **\$405 million for FY 2010**, an increase of \$32 million over the FY 2009 level. This will ensure that adequate resources are available for high priority research, including women's health care, sex and gender-based analyses, Medicare, and health disparities.

In conclusion, Mr. Chairman, we thank you and this Committee for its strong record of support for medical and health services research and its unwavering commitment to the health of the nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

**Written Testimony to the House Labor-Health and Human Services-Education  
Appropriations Subcommittee  
Regarding Fiscal Year 2010 Funding for the National Spina Bifida Program**

**Scott T. Price, Esq., President Spina Bifida Foundation  
Submitted on behalf of the Spina Bifida Association and the Spina Bifida Foundation  
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May 1, 2009**

**Funding Request Overview**

The Spina Bifida Association (SBA) and the Spina Bifida Foundation (SBF) respectfully request that the Subcommittee provide the following allocations in Fiscal Year (FY) 2010 to help improve quality-of-life for people with Spina Bifida:

- \$7 million for the National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) to support existing program initiatives and allow for the further development of the National Spina Bifida Patient Registry.
- \$4.818 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other neural tube defects.
- \$25.623 million to strengthen the CDC's National Birth Defects Prevention Network.
- \$77.059 million for the CDC's National Center on Birth Defects and Developmental Disabilities.
- \$405 million for the Agency for Healthcare Research and Quality (AHRQ).
- \$33.349 billion for the National Institutes of Health (NIH) to support biomedical research.

As you may know, a bipartisan group of 21 Representatives have submitted a letter to the Subcommittee in support of a \$7 million FY 2010 allocation for the National Spina Bifida Program; this effort was spearheaded by Representatives Bart Stupak and Chris Smith, co-chairs of the Congressional Spina Bifida Caucus.

**Background on Spina Bifida**

On behalf of the more than 185,000\* individuals and their families who are affected by Spina Bifida – the nation's most common, permanently disabling birth defect - SBA and SBF appreciate the opportunity to submit written testimony for the record regarding FY 2010 funding for the National Spina Bifida Program and other related Spina Bifida initiatives. SBA is a national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. The Spina Bifida Foundation assists SBA in its fundraising and advocacy efforts. SBA and SBF stand ready to work with Members of Congress and other stakeholders to ensure our nation mounts and sustains a comprehensive effort to reduce and prevent suffering from Spina Bifida.

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\* At the First World Congress on Spina Bifida Research and Care in March 2009 representatives from the CDC reported on new data indicating that there are an estimated 185,000 individuals living with Spina Bifida in the U.S.

*Spina Bifida Association and Spina Bifida Foundation  
Testimony to the House Labor-Health and Human Services-Education  
Appropriations Subcommittee  
FY 2010 Funding for the National Spina Bifida Program*

Spina Bifida, a neural tube defect, occurs when the spinal cord fails to close properly within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy – as the fetus grows – the spinal cord is exposed to the amniotic fluid, which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild – with little or no noticeable disability – to severe – with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most people with it suffer from a host of physical, psychological, and educational challenges – including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls, which seeks to ameliorate their condition by helping to relieve cranial pressure associated with spinal fluid that does not flow properly. As we have testified previously, the good news is that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living into adulthood and increasingly into their advanced years. These gains in longevity, principally, are due to breakthroughs in research, combined with improvements generally in health care and treatment. However, with this extended life expectancy, our nation and people with Spina Bifida now face new challenges – education, job training, independent living, health care for secondary conditions, and aging concerns, among others. Individuals and families affected by Spina Bifida face many challenges – physical, emotional, and financial. Fortunately, with the creation of the National Spina Bifida Program in 2003, individuals and families affected by Spina Bifida now have a national resource that provides them with the support, information, and assistance they need and deserve.

As is discussed below, the daily consumption of 400 micrograms of folic acid by women of childbearing age prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce the incidence of Spina Bifida, by up to 70 percent. However, 1,500 babies are still born each year with Spina Bifida, and, as such, with the aging of the Spina Bifida population and a steady number of affected births annually, the nation must take additional steps to ensure that all individuals living with this complex birth defect can live full, healthy, and productive lives.

#### **Cost of Spina Bifida**

It is important to note that the lifetime costs associated with a typical case of Spina Bifida – including medical care, special education, therapy services, and loss of earnings – are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare programs. The emotional, financial, and physical toll and costs of Spina Bifida on the individuals and families affected are extraordinary. Efforts to reduce and prevent suffering from Spina Bifida help to save money and save – and improve – lives.

*Spina Bifida Association and Spina Bifida Foundation  
Testimony to the House Labor-Health and Human Services-Education  
Appropriations Subcommittee  
FY 2010 Funding for the National Spina Bifida Program*

**Improving Quality-of-Life through the National Spina Bifida Program**

SBA has worked with Members of Congress to help improve our nation's efforts to prevent Spina Bifida and diminish suffering – and enhance quality-of-life – for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. The CDC's National Spina Bifida Program works on two critical levels – to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the individuals affected by Spina Bifida. Moreover, the National Spina Bifida Program works to improve the outlook for a life challenged by this complicated birth defect – principally, identifying valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need.

The National Spina Bifida Program serves as a national center for information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergies, obesity, skin breakdown and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. All of these problems can be treated or prevented, but only if those affected by Spina Bifida – and their caregivers – are properly educated and taught what they need to know to maintain the highest level of health and well-being possible. The National Spina Bifida Program's secondary prevention activities represent a tangible quality-of-life difference to the 185,000 individuals living with Spina Bifida with the goal being living well with Spina Bifida.

One way to enhance the knowledge base of Spina Bifida, improve quality of care, and save precious resources is to establish a patient registry for Spina Bifida. Plans are underway to create the National Spina Bifida Patient Registry. This registry is intended to determine the best clinical practices and the most cost effective treatment for Spina Bifida, as well as, support the creation of quality measures to improve overall care. It is only through clinical research towards improved care that we can truly save lives, while also realizing a significant cost savings.

In FY 2009, SBA requested \$7 million be allocated to support and expand the National Spina Bifida Program. In the final FY 2009 Omnibus Appropriations Act, Congress provided \$5.468 million for this program, following three years of essentially flat funding. SBA understands that the Congress and the nation face unprecedented budgetary challenges and, as such, appreciates this modest increase. However, the progress being made by the National Spina Bifida Program must be sustained and expanded to ensure that people with Spina Bifida – over the course of their lifespan – have the support and access to quality care they need and deserve. To that end, SBA respectfully urges the Subcommittee to Congress allocate \$7 million in FY 2010 to the

*Spina Bifida Association and Spina Bifida Foundation  
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FY 2010 Funding for the National Spina Bifida Program*

program so it can continue and expand its current scope of work; further develop the National Spina Bifida Patient Registry; and sustain the National Spina Bifida Resource Center. Increasing funding for the National Spina Bifida Program will help ensure that our nation continues to mount a comprehensive effort to prevent and reduce suffering from – and the costs of – Spina Bifida.

**Preventing Spina Bifida**

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty-five million women of child-bearing age are at-risk of having a child born with Spina Bifida, and each year approximately 3,000 pregnancies in this country are affected by Spina Bifida, resulting in an estimated 1,500 births. As mentioned above, the daily consumption of 400 micrograms of folic acid prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce the incidence of Spina Bifida, by up to 70 percent. There are few public health challenges that our nation can tackle and conquer by nearly three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 30 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age – particularly those most at-risk for a Spina Bifida pregnancy – consume adequate amounts of folic acid prior to becoming pregnant.

The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain a diet rich in folic acid. Since 1968, the CDC has led the nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. This public health success should be celebrated, but still too many women of childbearing age consume inadequate daily amounts of folic acid prior to becoming pregnant, and too many pregnancies are still affected by this devastating birth defect. The nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call – such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBA is the managing agent for the National Council on Folic Acid, a multi-sector partnership reaching more than 100 million people a year with the folic acid message. The goal is to increase awareness of the benefits of folic acid, particularly for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves, or those who have already conceived a baby with Spina Bifida). With additional funding in FY 2010, CDC's folic acid awareness activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBA advocates that Congress provide additional funding to CDC to allow for a targeted public health education and awareness focus on at-risk populations (e.g., Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.



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In addition to a \$7 million FY 2010 allocation for the National Spina Bifida Program, SBA urges the Subcommittee to provide \$4.818 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other neural tube defects; \$25.623 million to strengthen the CDC's National Birth Defects Prevention Network; and a total of \$77.059 million for the National Center on Birth Defects and Developmental Disabilities.

**Improving Health Care for Individuals with Spina Bifida**

As you know, AHRQ's mission is to improve the outcomes and quality of health care, reduce health care costs, improve patient safety, decrease medical errors, and broaden access to essential health services. AHRQ's work is vital to the evaluation of new treatments, which helps ensure that individuals living with Spina Bifida continue to receive state-of-the-art care and interventions. To that end, we request a \$405 million FY 2010 allocation for AHRQ, so it can continue to provide guidance and support to the National Spina Bifida Patient Registry.

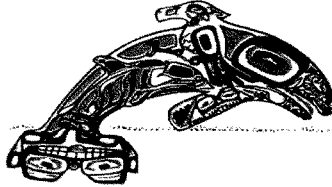
**Sustain and Seize Spina Bifida Research Opportunities**

Our nation has benefited immensely from our past federal investment in biomedical research at the NIH. SBA joins with other in the public health and research community in advocating that NIH receive \$33.349 billion in FY 2010. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA respectfully requests that the Subcommittee include language in the report accompanying the FY 2010 LHHS appropriations measure:

- Urging the National Institute of Child Health and Human Development (NICHD) to continue to support – and expand – a more comprehensive Spina Bifida research portfolio that focuses on addressing the myriad secondary effects and conditions associated with Spina Bifida;
- Commending the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for its interest in exploring issues related to the neurogenic bladder and to encourage the institute to forge ahead with its work in this important topic area; and
- Encouraging the National Institute of Neurological Diseases and Stroke (NINDS) to continue and expand its research related to the treatment and management of hydrocephalus.

**Conclusion**

Please know that SBA and SBF stand ready to work with the Subcommittee and other Members of Congress to advance policies and programs that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views regarding FY 2010 funding for programs that will improve the quality-of-life for the 185,000 Americans and their families living with Spina Bifida.



## SQUAXIN ISLAND TRIBE

### Tribal Representatives

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WRITTEN STATEMENT SUBMITTED TO THE  
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES  
FOR THE FY 2010 BUDGET FOR  
THE DEPARTMENT OF HEALTH AND HUMAN SERVICES  
DAVE LOPEMAN, CHAIRMAN  
MAY 1, 2009

Thank you, distinguished Members of this Subcommittee, for accepting this written statement on the FY 2010 Budget for the Department of Health and Human Services from the Tribal Members of the Squaxin Island Tribe, a signatory of the 1854 Medicine Creek Treaty. We are providing requests for consideration by the Subcommittee to advance the tenets of Indian Self-Determination, Tribal Self-Governance, and government-to-government relations between the United States and American Indians and Alaskan Natives.

### Squaxin Island Priorities:

- \$400,000 to implement Electronic Health Record funding only for Direct Service Tribes; Self-Governance Tribes have not received funding. Need additional funding in Department-wide budget for Electronic Records.
- Centers for Medicare and Medicaid Services (CMS)
  - \$1.8 million - Request current Medicaid funding (\$800,000) for Squaxin beneficiaries to be transferred into recurring funds; and an additional \$1 million or status quo
  - \$3 million - Support Tribal Technical Advisory Group recommendation in 2010-2015 Strategic Plan.
- Administration for Children and Families (ACF)
  - Adequate funding for Indian Child Welfare (Title IV-E) Authority

The Squaxin Island Tribe has an enrollment of 1,008 and an on-reservation population of 400 living in 129 homes. Squaxin has an estimated service area population of 2,747, a growth rate of about 10%, and an unemployment rate of about 30%, according to the BIA Labor Force Report.

The Tribe requests a onetime appropriation of \$400,000 for the implementation of an Electronic Health Record system. The Squaxin Island Tribe is anxiously waiting to learn if IHS or HHS will assist the Tribe as it implements the IHS Electronic Health Record this year in our health program. The estimated implementation cost of \$400,000 and ongoing costs are too high for the Tribe to bear on its own and we are hopeful that the Department of Health and Human Services

can provide direct funding for this implementation since the proposed mechanism of enhanced provider payments will not work for Indian health programs. We are concerned that since the Indian Health Service has already implemented EHR in Direct Service Tribes' programs that they are not likely to provide funding for Self-Governance Tribes.

During the current recession additional tribal members are likely to increasingly rely on health service paid by Medicaid. Likewise, our Health Program depends on the payments from Medicare and Medicaid to provide health care services. Nearly 30% of our health programs revenues currently come from CMS payments for these two programs. The Squaxin Island Tribe's 1854 treaty and its guarantee of medical services (and a physician) could be easily honored by simply *converting Medicaid funds currently received by the Tribe (about \$800,000) into recurring funding with an additional appropriation of about \$1 million.* Honorable nations honor their treaties. Only about \$1 million stands between the status quo of means testing every Tribal member for health care services and honoring the promise made in 1854.

The Squaxin Island Tribe strongly supports the President's and the Congress funding increases for the Medicaid program. We are concerned; however, that CMS does not adequately fund its Tribal Technical Advisory Group. *The Tribe supports the funding recommendations (of about \$3 million) contained in the 2010-2015 Strategic Plan of the Tribal Technical Advisory Group.*

In addition to these requests we seek the Committee's support for adequate funding for the Indian Child Welfare Authority (Title IV-E) that will allow Tribes to receive direct funding from the federal government.

The Squaxin Island Tribe Health and Human Services Department works with other partners including other Tribes and Tribal organizations to provide the full range of Health and Social Services to tribal members and our larger community. Health Care services are the largest component of these services with funding received from not only the Indian Health Service, but also the Centers for Medicare and Medicaid Services (CMS) and the other health agencies of the Department of Health and Human Services (DHHS) funded by the HHS appropriation.

Thanks you for providing me this opportunity to present our priorities for the Department of Health and Human Services.

**PUBLIC WITNESS TESTIMONY FOR THE RECORD**

**Name:** Travis Robinette  
**Title:** CEO  
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Community Health Centers in Arizona serve a critical role in meeting healthcare needs in Arizona (which is a predominantly rural state). I believe that Sun Life Family Health Center is among the leading community health centers in Arizona and the United States. In terms of our vision, Sun Life firmly believes that every individual is entitled to accessible quality healthcare services without regard for age, sex, ethnicity or ability to pay.

The overall mission of the Center is "to deliver comprehensive, high quality services to all people in the need of affordable, accessible and culturally effective primary care." Sun Life's market segment all of Pinal County, grew exponentially over the past five years to the current of 299,875 residents. This represents an increase of approximately 20% a year since 2000. *Currently, Pinal County Arizona is the second fastest growing county in the United States* and this translates into critical infrastructure needs for the expansion of current facilities to meet the growing requirements to meet the needs for enhanced primary care services.

Approximately 50% of patients seen by Sun Life Family Health Center are Hispanic, 59% are children from the ages of 5-14 years of age; and 13% are senior citizens. Sun Life is proud to promote their efforts in serving all populations equally with price conscious and "Gold Standard" primary health care as mandated by the Joint Commission. In addition, Sun Life is the only primary care facility that provides its services on a sliding fee scale-based basis and no patient is turned away.

The medical staff has seen dramatic changes within 40,000 patients that visited the six clinics that Sun Life oversees. During 2008, the diagnosis of patients with diabetes increased by 60%; patients diagnosed with hypertension increased 52%; there was a 58% increase in cervical cancer; 32% increase in abnormal breast findings; an alarming increase of 91% in prenatal conditions; and an increase of 59% in the treatment of asthma and other medical conditions.

National trends in the political and economic arenas are creating an environment that continues to create new challenges for Sun Life to effectively diagnose and treat patients with those conditions and others because as the population grows both geometrically and proportionately the number of potential patients with limited or no access to coverage also increases.

The access to coverage is not solely indicative of uninsured patients, but also with insured patients whose health insurance companies continue to make changes to

coverage for the sake of the bottom line. A significant contrast from Sun Life's bottom line is rooted in the holistic approach to the total health and wellness of the patient throughout their life span. This includes providing affordable prescriptions for those on limited incomes (e.g., senior citizens) and reducing health disparities among children and minorities.

With this in mind, Sun Life Family Health Center has submitted a request to Congresswoman Kirkpatrick's office for \$1,825,000 for Health Information Technology and has been submitted on our behalf by her office for consideration of appropriation funding. Health Information Health Technology remains at the forefront of effective healthcare management, essential to financial viability as well as the ability to provide affordable, quality health care to patients.


Sun Life's long-term aim here is to balance individual privacy protections with the use of innovative technologies that will modernize the Sun Life healthcare system, reduce medical errors and allow primary care physicians to better track treatments, medications and laboratory tests. In addition, we wish to grant patients the right to limit disclosure only to individuals involved directly with their health care, and the right to view and supplement their medical records.

The tracking of care for planning and/or reporting purposes of patient outcomes is important for sharing of best practices with other state and national Community Health Centers. Once installed, Health Information Technology will serve to dramatically improve quality of care while reducing overall costs to the federal government and tax payers.

*Therefore, on behalf of Sun Life Family Health Center, I strongly urge the Subcommittee on Labor, Health and Human Services, Education and Related Agencies Committee on Appropriations to support Congresswoman's Kirkpatrick's request on our behalf and fund this project.*

Thank you for your kind consideration.

Sincerely,



Travis Robinette, CEO  
Sun Life Family Health Center

*Submitted by: Stephanie Kutler, Director, Government Affairs, The Endocrine Society; 301-941-0254; skutler@endo-society.org*

**FY 2010 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY  
SUBMITTED BY THE ENDOCRINE SOCIETY  
FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES  
DIRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN  
SERVICES/NATIONAL INSTITUTES OF HEALTH**

The Endocrine Society is pleased to submit the following testimony regarding Fiscal Year 2010 federal appropriations for biomedical research, with an emphasis on appropriations for the National Institutes of Health (NIH). The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing over 14,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of researchers who depend on federal support for their careers and their scientific advances.

Since the doubling of its budget, the NIH has received annual funding increases below the rate of biomedical inflation. FY 2009 appropriations resulted in the first real-dollar increase in NIH funding since FY 2003. This decline in useable dollars has resulted in a significant decrease in the number of R01 grants funded. In 2003, the number of new and continuing R01s was 7,211; the number of grants awarded in 2008 dropped to 5,886. As a result of the decreasing number of grants awarded, the success rate for new R01 grants dropped from 25.5 percent in 1999 to a low of 16.3 percent in 2006 (the 2008 success rate was 19 percent). Not only does the decline in grants affect the number of scientists who are able to continue their research and discover new treatments and cures, it also has a significant impact on the United States economy.

In fiscal year 2007, every \$1 million that the public invested in NIH research generated \$2.21 million in new business activity across the nation. At a recent House Energy and Commerce Committee hearing, Dr. Raynard Kington, Acting Director of the NIH, stated that each NIH grant supports seven jobs on average. Since grants are dispersed to all 50 states and 90 percent of congressional districts, increasing funding for science will have a significant positive impact on job growth. And unlike many other proposals to stimulate the economy, funding NIH grants can have an immediate impact on the economy because these grants can be funded in a matter of weeks, stimulating local economies through salaries and purchase of equipment, laboratory supplies, and vendor services.

Members of Congress and President Obama recognized the positive impact that funding NIH research can have on the economy and allocated over \$10 billion to the NIH in the American Recovery and Reinvestment Act of 2009. These funds will go a long way towards increasing the success rate of new R01 applications, keeping scientists employed, and creating new jobs. The Endocrine Society thanks Congress for the support of biomedical research funding in the ARRA.

However, the federal government needs to make a long-term, sustainable commitment to biomedical research funding. The money allocated to the NIH in the ARRA is a one-time infusion of money, and it is unclear how much NIH's budget will be when the stimulus funds run out at the end of FY 2010. These funds will create thousands of new jobs, most of which will end when FY 2011 begins if Congress does not bring NIH's budget closer to \$40 billion than to \$30 billion. The loss of these jobs could have a drastic effect on our economy and counteract the benefits realized during FY 2009 and 2010 as a result of the stimulus funding.

While the nation is struggling with a failing economy, health reform is also on the top of the minds of members of Congress and the American people. With the aging of the Baby Boomer generation, the incidence of costly, chronic conditions will significantly increase, and a large portion of the projected increase in health care costs will be as a result of escalating costs associated with diabetes, obesity, hypertension, Alzheimer's disease, muscular dystrophy, cystic fibrosis, and stroke. In order to prevent and treat these diseases, and save the country billions in healthcare costs, significant investment in biomedical research will be needed. For instance, treatments that delay or prevent diabetic retinopathy save the country \$1.6 billion a year, and new treatments that delay the onset and progression of Alzheimer's disease by five years can save \$50 billion a year in health care costs.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. The Society strongly supports the continued increase in federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address the burgeoning scientific opportunities and new health challenges that continue to confront us. The Endocrine Society supports President Obama's campaign pledge to double the NIH budget over ten years. We therefore recommend that NIH receive an increase of at least seven percent in FY 2010 to prepare for the post-stimulus era and ensure the steady, sustainable growth necessary to complete the President's vision of doubling the investment in basic and clinical research.

Submitted by:  
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**The Society for Healthcare Epidemiology of America (SHEA)**  
**Statement on Fiscal Year 2010 Funding for the U.S. Department of Health and Human**  
**Services (HHS), the Centers for Disease Control and Prevention (CDC),**  
**and the National Institutes of Health (NIH)**

SHEA was founded in 1980 to advance the application of the science of healthcare epidemiology. SHEA works to achieve the highest quality of patient care and healthcare personnel safety in all healthcare settings by applying epidemiologic principles and prevention strategies to a wide range of quality-of-care issues. SHEA is a growing organization, strengthened by its membership in all branches of medicine, public health, and healthcare epidemiology.

SHEA and its members are committed to implementing evidence-based strategies to prevent healthcare-associated infections (HAIs). SHEA members have scientific expertise in evaluating potential strategies for eliminating preventable HAIs. We collaborate with a wide range of infection prevention and infectious disease societies, specialty medical societies in other fields, quality improvement organizations, and patient safety organizations in order to identify and disseminate evidence-based practices.

Our principal partners in the private sector are sister societies such as the Infectious Diseases Society of America (IDSA) and the Association of Professionals in Infection Control and Epidemiology (APIC). The Centers for Disease Control and Prevention (CDC), its Division of Healthcare Quality Promotion (DHQP) and the federal Healthcare Infection Practices Advisory Committee (HICPAC), and the Council of State and Territorial Epidemiologists (CSTE) have been invaluable federal partners in the development of guidelines for the prevention and control of HAIs and in their support of translational research designed to bring evidence-based practices to patient care. Further, collaboration between experts in the field (epidemiologists and infection preventionists), CDC and the Agency for Healthcare Research and Quality (AHRQ) plays a critical role in defining and prioritizing the research agenda. More recently, SHEA has aligned with the Joint Commission and the American Hospital Association to produce and promote the implementation of evidence-based recommendations in the *Compendium of Strategies to Prevent Healthcare-Associated Infections in Acute Care Hospitals* (<http://www.shea-online.org/about/compendium.cfm>). The organization also contributes expert scientific advice to quality improvement organizations such as the Institute for Healthcare Improvement (IHI), the National Quality Forum, and state-based task forces focused on infection prevention and public reporting issues.

The current swine flu emergency and the Obama Administration's request for an additional \$1.5 billion to address the situation highlights the need for ongoing congressional support of a



national prevention strategy and dedicated funding stream for core public health programs. It is our hope that health reform can serve as an opportunity to strengthen our public health infrastructure and reorient our health system towards prevention and preparedness.

SHEA applauds the Congress for its support of HAI prevention and reduction activities through the American Recovery and Reinvestment Act (ARRA) and the FY 2009 Omnibus Appropriations bill. The Society is collaborating with the Department of Health and Human Services (HHS) and the CDC to translate agency goals and objectives for these funds into actions at the bedside that can achieve meaningful reductions in preventable HAIs. However, SHEA believes that this level of funding is substantially insufficient to address a problem estimated by CDC to be one of the top ten causes of death in the nation and one that poses a significant economic burden on the nation's healthcare system.

SHEA supports the conclusions of last year's GAO report on coordination among HHS agencies related to HAI prevention. We believe that coordinated action among CDC, the Centers for Medicare & Medicaid Services (CMS) and the Agency for Healthcare Research and Quality (AHRQ) is critical. CDC and its Division of Healthcare Quality Promotion should function as the lead agency in surveillance and prevention activities related to HAIs at the federal level because of its historic and successful role in this area. CDC has had an enviable track record of prevention and its development and management of the foremost surveillance system of its kind, the National Healthcare Safety Network (NHSN) has created a national resource that many states have now mandated as their public reporting tool. Furthermore, guidelines developed by the HICPAC are widely regarded as the standards for the field. Coordinated activity among the agencies can lead to better informed public policy and payment reform.

Clearly, the CDC plays a critical role in public health protection through its health promotion, prevention, preparedness and research activities. As you consider FY 2010 funding levels for the CDC, **SHEA urges your support of at least \$8.6 billion for CDC's "core programs"** [not including the mandatory funding provided for the Vaccines for Children Program (VFC)] to ensure that the agency is able to carry out its prevention mission and to assure an adequate translation of new research into effective state and local programs. In addition to maintaining a strong public health infrastructure and protecting Americans from public health threats and emergencies, SHEA strongly believes that CDC programs play a vital role in reducing healthcare costs and improving the public's health.

Within this total, SHEA recommends a FY 2010 funding level of **\$2.4 billion for CDC's Infectious Diseases program budget** which supports vital management and coordination functions for infectious disease science, program, and policy, including infectious disease specific epidemiology and laboratory activities. In particular, SHEA believes that protecting and improving resources for implementation of programs that standardize measurement of appropriate HAI outcomes and performance measures should be a priority. Our most valuable resource in this regard is NHSN, a voluntary, secure, internet-based surveillance system that integrates and expands patient and healthcare personnel safety surveillance systems. Many states consider NHSN to be the best option for implementing standardized reporting of HAI data. NHSN has now been adopted by 19 states and more than 2,100 US hospitals for the surveillance and reporting of HAIs. It is an enormously important national resource and effective funding

and support is essential to expand its implementation. Further, recognizing that multiple states mandate the use of NHSN for state public reporting, immediate efforts should be made to enable interfaces between electronic health records (EHRs) and NHSN. In this way, additional burdens are not placed upon healthcare entities from either an infection prevention and control or information technology (IT) perspective as the desirability for national database integration proceeds.

As already noted, SHEA believes that **additional federal dollars should be appropriated for HAI prevention and reduction to build upon the investment already made through the ARRA and FY 2009 Omnibus Appropriations bill.** It is SHEA's perspective that additional funding in this area will have the greatest impact when prioritized in the following ways:

- SHEA strongly encourages an emphasis on implementation of **evidence-based practices (EBP)**, as supported by guidelines (CDC-HICPAC) and evidence-based recommendations (*Compendium of Strategies to Prevent Healthcare-Associated Infections in Acute Care Hospitals*). Protecting the health of our patients and preventing HAIs in the settings where healthcare is delivered in the United States will require a multi-faceted approach that includes identification and widespread adoption of evidence-based best practices. Where evidence does not exist, uniformity in practice should be adopted and studied to determine effectiveness. Failed practices should be discarded and successes widely disseminated. Prevention and control of HAIs also will require better tools in the form of new and novel antimicrobial agents, better knowledge of strategies to effect implementation and adherence to proven prevention methods, and accountability for performance.
- SHEA supports investment in **training and education programs** for both hospital-wide personnel, local public health personnel and patients/families in evidence-based prevention practices and development of educational materials /tools for patients and families with respect to HAI and multiple drug resistant organisms (MDRO).
- SHEA supports a **broad context for use of dollars for HAIs** rather than pathogen-specific targets or mandates (e.g., on MRSA or *C. difficile*). Ideally, funding should be tied to locally identified priorities emphasizing that implementation of best practice bundles for catheter-associated bloodstream infections (CLA-BSI), ventilator-associated pneumonia (VAP) and catheter-associated urinary tract infection (CA-UTI) will have a greater impact on prevention of HAIs, including those due to MDRO, than pathogen-specific practices. This approach recognizes the influence of local conditions on the control of healthcare-associated infections, and allows rapid modification of strategies as new knowledge is gained. As an example, SHEA and CMS emphasize that a risk assessment must be the first step in any epidemiologic study or infection prevention and control program in order to target preventive efforts effectively. We are pleased that the Joint Commission supports this critical step by developing it into a basic infection prevention standard. SHEA believes that this strategy allows healthcare facilities to use local information to develop and implement optimal and individualized prevention plans designed to reduce healthcare-associated infections that are identified as local problems. Goals should be written in such a way to allow hospitals the flexibility to identify and

target their own safety threats within the domains that are considered critical, and healthcare facilities should be expected to be able to justify their infection prevention program based on local risk assessments.

- SHEA supports investment in **hospital infrastructure** and qualified personnel for infection prevention and control including epidemiologists, infection prevention and control professionals, NHSN implementation, and adequate microbiology/lab diagnostic capability as dictated by locally derived needs assessment and priority.
- SHEA believes that **funds made available through CDC and AHRQ should be used, in part, for translational research projects that can allow more rapid integration of science into practice.** As an example, this could involve use of funds to support positions through which large collaboratives could be supported in states not currently part of AHRQ or HRET projects (for example PHRI and Keystone, which have achieved successful reductions in device-associated infections). Experts in the field (Epidemiologists and Infection Preventionists), in collaboration with CDC and the AHRQ, should be engaged in order to further define and prioritize the research agenda. As we strive to eliminate all preventable HAIs, we need to identify the gaps in our understanding of what is actually preventable. This distinction is critical to help guide subsequent research priorities and to help set realistic expectations. SHEA believes in the importance of conducting basic, epidemiological and translational studies (to fill basic and clinical science gaps). While health services research (i.e., successful implementation of strategies already known or suspected to be beneficial) may provide some immediate short-term benefit, to achieve further success, **a substantial investment in basic science, translational medicine, and epidemiology is needed** to permit effective and precise, interventions that prevent HAIs.
- SHEA strongly favors **local decision-making about priorities for use of funds;** however, state efforts should be aligned with CDC priorities and should be carried out through collaboration with key stakeholders such as state hospital associations and local experts. CDC should lead the effort to measure and report on the success of state prevention efforts to HHS.

With respect to the National Institutes of Health (NIH), SHEA is very pleased that the American Recovery and Reinvestment Act infused the Institutes with billions of dollars for research projects that will enable growth and investment in biomedical research and development, public health and health care delivery. The NIH is the single-largest funding source for infectious diseases research in the US and the life-source for many academic research centers. The NIH-funded work conducted at these centers lays the ground work for advancements in treatments, cures, and medical technologies. We applaud Congress for acknowledging the impact of scientific research in stimulating the economy.

SHEA believes that any national effort designed to address the problem of HAIs should begin with the following principles: scrutiny of the science base; development of an aggressive, prioritized research agenda; the conduct of studies that address the identified questions; creation

and deployment of guidelines based on the outcomes of these studies, followed by studies that assess the efficacy of the intervention.

In order to determine the preventability of infections, we first need to understand how and why these infections occur. A comprehensive national research agenda on HAIs must include at least three major categories of research: pathogenesis, epidemiology, and infection prevention strategies. A fourth area of, perhaps, even greater importance is the development and use of improved approaches to the design of healthcare epidemiology studies. Carefully designed multicenter prospective clinical trials are needed to establish the effectiveness of prevention and control strategies.

Unfortunately, support for basic, translational, and epidemiological research on HAIs has not been a priority of major funding bodies. Despite the fact that HAIs are among the top ten annual causes of death in the US, scientists studying these infections have received relatively less funding than colleagues in many other disciplines. In 2008, NIH estimated that it spent more than \$2.9 billion dollars on funding for HIV/AIDS research, about \$2.0 billion on cardiovascular disease research, about \$664 million on obesity research and, by comparison, National Institute of Allergy and Infectious Diseases (NIAID) provided \$18 million for MRSA research. SHEA believes that as the magnitude of the HAI problem becomes part of the dialogue on health care reform, it is imperative that the Congress and funding organizations put significant resources behind this momentum.

The limited availability of federal funding to study HAIs has the effect of steering young investigators interested in pursuing research on HAIs toward other, better-funded fields. While industry funding is available, the potential conflicts of interest, particularly in the area of infection-prevention technologies, make this option seriously problematic. These challenges are limiting professional interest in the field and hampering the clinical research enterprise at a time when it should be expanding.

Our discipline is faced with the need to bundle, implement and adhere to interventions we believe to be successful while simultaneously conducting basic, epidemiological, pathogenetic and translational studies that are needed to move our discipline to the next level of evidence-based patient safety. The current convergence of scientific, public and legislative interest in reducing rates of HAIs can provide the necessary momentum to address and answer important questions in HAI research. SHEA strongly urges you to **enhance NIH funding for FY 2010 to ensure adequate support for the research foundation that holds the key to addressing the multifaceted challenges presented by HAIs.**

SHEA thanks for the committee for this opportunity to share our priorities with respect to Fiscal Year 2010 funding for HHS, CDC and the NIH. The Society is pleased to serve as a resource to the committee going forward on issues related to healthcare epidemiology.

Testimony of the Tri-Council for Nursing  
Regarding FY 2010 Appropriations for Nursing Workforce Development Programs  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives

May 1, 2009

The Tri-Council for Nursing, a long-standing alliance focused on leadership and excellence in the nursing profession, is composed of the American Association of Colleges of Nursing, the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing. The collaborative leadership of these four professional organizations impacts the breadth of nursing practice, including nurse executives, educators, researchers, and nurses providing direct patient care. The Tri-Council asks the Subcommittee **to provide \$215 million in FY 2010 for the Nursing Workforce Development Programs under Title VIII of the *Public Health Service Act***, administered by the Health Resources and Services Administration (HRSA).

In light of the economic challenges facing our country today, the Tri-Council urges the Subcommittee to focus on the larger context of building the capacity needed to meet the increasing health care demands of our nation's population. Such public policy will require sustained investments aimed at refocusing the current health care system toward promoting health, while simultaneously improving value for our dollars. The Title VIII Nursing Workforce Development Programs are proven policy instruments that help assure an adequately prepared nursing workforce. These programs

- Increase access to health care in underserved areas through improved composition, diversity, and retention of the nursing workforce;
- Advance quality care by strengthening nursing education and practice; and
- Develop the identification and use of data, program performance measures, and outcomes to make informed decisions on nursing workforce matters.

The Tri-Council applauds the Subcommittee for the emergency supplement provided across all the health professions programs via the American Recovery and Reinvestment Act (P.L. 111-5). We also value the enacted FY 2009 Omnibus Appropriations bill (P.L. 111-8) providing \$171.031 million specifically for the Title VIII Nursing Workforce Development Programs. These investments are a critical component supporting our health care infrastructure.

Examining the broad context, the health care industry remains the largest industrial complex in the United States. Studies of the nation's gross domestic product (GDP) show health care spending achieving a relatively high rate of real growth, with the portion of GDP devoted to health care growing from 8.8 percent in 1980 to 16.2 percent of GDP in 2007. While health care spending demands greater efficiencies, it also has helped to sustain our nation's sagging economy.

Since 2001, health care is virtually the only sector that added jobs to the economy on a net basis. In March 2009, the U.S. Bureau of Labor Statistics (BLS) reported continued growth in the health care sector, despite our economy's freefall in a down cycle with unemployment reaching 8.1 percent in

February 2009. With that month's job-loss of 681,000 realized in nearly all major industries, BLS also reported the addition of 27,000 new jobs at hospitals, long-term care facilities, and other ambulatory care settings.

As the predominant occupation in the health care industry, the nurse workforce likely is filling most of the noted job openings. Nurses are the front line of health care delivery throughout the nation, and the BLS numbers support that description showing the nurse workforce at well over four times the size of the medical workforce. Increased FY 2010 investments in Title VIII will help counterbalance the economic meltdown threatening nursing programs operating in congressional districts and serving communities by supporting nursing education – providing Title VIII loans, scholarships, traineeships, and programmatic funding.

### **Nursing Shortage Outpaces Capacity-Building**

The Tri-Council contends that an episodic increased funding of Title VIII will not fully fill the gap generated by an eleven-year nursing shortage felt throughout the entire U.S. health system and projected to continue. The BLS projections estimate that RNs will have the greatest growth rate of all U.S. occupations in the period spanning 2006 – 2016, with more than one million new and replacement nurses needed by 2016. Despite this projected expansion in the profession, numerous other studies anticipate a growing national nurse workforce shortage to intensify as the baby boomer cohort ages, the current nurse workforce retires, and the demand for health care accrues.

Funding levels for the HRSA Title VIII Nursing Workforce Programs are failing to support the numerous qualified applicants seeking assistance from these programs. In the last three years, virtually flat Title VIII funding, along with inflation and increased educational and administrative costs, has decreased purchasing power. According to HRSA statistics, in FY 2006 the Title VIII programs directly or indirectly supported 91,189 nurses and nursing students. In FY 2007, the number of grantees dropped by 21 percent and in 2008 the grantees dropped by 28 percent to support only 51,657 nurses and nursing students.

Additionally, schools of nursing continue to suffer from a growing shortage of faculty, a troubling infrastructure trend that exacerbates the nurse workforce demand-supply gap. According to a study conducted by the American Association of Colleges of Nursing (AACN) in 2008, schools of nursing turned away 49,948 qualified applicants to baccalaureate and graduate nursing programs. The top reasons cited for not accepting these potential students was a lack of qualified nurse faculty and resource constraints. Without faculty, nursing education programs are prevented from admitting many qualified students who are applying to their programs. (Data are Internet accessible at <http://www.aacn.nche.edu/Media/NewsReleases/2009/workforcedata.html>.)

The AACN survey results are reinforced by the National League for Nursing's (NLN) study of all types of prelicensure RN programs, which prepare students to sit for the RN licensing exam (i.e., baccalaureate, associate, and diploma degree). The NLN statistics indicate over 1,900 unfilled full-time faculty positions existed nationwide in 2007, affecting over one-third (36 percent) of all schools of nursing. Significant recruitment challenges were found with 84 percent of nursing schools attempting to hire new faculty in 2007-2008, over three-quarters (79 percent) reporting recruitment as "difficult" and almost 1 in 3 schools found it "very difficult." The two main difficulties cited were

“not enough qualified candidates” (cited by 46 percent of schools), followed by inability to offer competitive salaries – cited by 38 percent. (Data are Internet accessible at [www.nln.org/research/slides/index.htm](http://www.nln.org/research/slides/index.htm).)

### The Funding Reality

If the United States is to reverse the eroding trends in the nurse and nurse faculty workforce, the nation must make a significant investment in the Title VIII programs, which are charged to favor institutions educating nurses for practice in rural and medically underserved communities. At adequate funding levels the Title VIII programs supporting the education of registered nurses, advanced practice registered nurses, nurse faculty, and nurse researchers have demonstrated successful intervention strategies to solving past nursing shortages.

A brief examination of the HRSA Title VIII illustrates the robust nature of these programs:

Section 811 – The Advanced Education Nursing (AEN) Program funds traineeships for individuals preparing to be nurse practitioners, nurse midwives, nurse administrators, public health nurses, and nurse educators, among other graduate-level education nursing roles. The AEN awards assisted nurse education programs to support 3,419 graduate nursing students in FY 2008.

Section 821 – The Nursing Workforce Diversity Program funds grants and contracts to schools of nursing, nurse-managed health centers (NMCs), academic health centers, state and local governments, and nonprofit entities to increase nursing education opportunities for individuals from disadvantaged backgrounds and under-represented populations among RNs. This program – of proven intervention strategies – supported 18,741 students in FY 2008, seeking to ensure a culturally diverse workforce to provide health care for a culturally diverse patient population.

Section 831 – The Nurse Education, Practice and Retention Program provides support for academic and continuing education projects designed to strengthen the nursing workforce. Several of this program’s priorities apply to quality patient care including developing cultural competencies among nurses and providing direct support to establishing or expanding NMCs in non-institutional settings to improve access to primary health care in medically underserved communities. The program also provides grants to improve retention of nurses and enhanced patient care. In FY 2008, approximately 6,000 nurses and nursing students were supported.

Section 846 – The Nurse Loan Repayment and Scholarship Programs is divided into two primary elements. The Nursing Education Loan Repayment Program (NELRP) assists individual RNs by repaying up to 85 percent of their qualified educational loans over three years in return for their commitment to work at health facilities with a critical shortage of nurses, such as departments of public health, community health centers, and disproportionate share hospitals. In FY 2008, of the 5,875 applications reviewed by HRSA, only 435 students (7.4 percent) received NELRP awards. Similarly, the Nurse Scholarship Program (NSP) provides financial aid to individual nursing students in return for working a minimum of two years in a health care facility with a critical nursing shortage. In FY 2008, NSP turned away most of the applicants owing to a lack of adequate funding, resulting in the distribution of only 169 student awards.

Section 846A – The Nurse Faculty Loan Program (NFLP) supports the establishment and operation of a loan fund within participating schools of nursing to assist RNs to complete their education to become nursing faculty. The NFLP grants provide a cancellation provision in which 85 percent of the loan, plus interest, may be cancelled over four years in return for serving as full-time faculty in a school of nursing. NFLP granted 729 awards in FY 2008.

Section 855 – The Comprehensive Geriatric Education Grant Program focuses on training, curriculum development, faculty development, and continuing education for nursing personnel caring for the elderly. In FY 2008, 18 awards were made in this program.

While Title VIII is the largest source of federal funding for nursing, the current level of investment falls short of remedying a chronic underfunding of the Nursing Workforce Development Programs, compared to the existing and imminent shortages these programs address. The Title VIII authorities are capable of providing flexible and effective support to assist students, schools of nursing, and health systems in their efforts to recruit, educate, and retain registered nurses. Recent efforts have shown that aggressive and innovative strategies can help avert the nurse and nurse faculty shortages. The Tri-Council for Nursing understands the competing priorities faced by this Congress, but we also maintain that Title VIII Nursing Workforce Development Programs must be funded at an adequate level to begin to impact the shortage and to address the complex health needs of the nation. The contributions of nurses in our health care system are multifaceted, and are impacted directly by the level of federal funding that supports nursing programs.

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Written Testimony of Jeffrey Levi, PhD  
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 House Appropriations Subcommittee on Labor, Health & Human Services, Education and  
 Related Agencies  
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My name is Jeff Levi, and I am Executive Director of Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority. I am grateful for the opportunity to submit testimony to the Subcommittee about public health appropriations.

Americans deserve a well-financed, modern, and accountable public health system. Funding for public health and disease prevention is a down payment toward reducing health care costs over the long term. Especially during an economic downturn, it is important to have a strong safety net to support individuals who are losing their health coverage. As unemployment rates soar, unemployed workers and their families turn to state and local health departments and community-based organizations for basic health services, like immunizations and preventive services that are provided free of charge to those who cannot afford them. Toward that end, we hope that you will consider an investment in wellness and prevention through the appropriations process as a means of offering assistance to struggling families. As you craft the FY 2010 Labor, Health & Human Services, Education and Related Agencies appropriations bill, I hope that you will include robust funding for prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and the Office of the Assistant Secretary for Preparedness and Response (ASPR) in order to promote health and help protect Americans from the threats posed by terrorism or natural threats such as pandemic influenza.

#### **Case for support**

There is increasing evidence that community level interventions, the kind of programs that CDC funding supports, make a difference in health outcomes and health care costs. In 2008, Trust for America's Health released a report, *Prevention for a Healthier America: Investments in Disease Prevention Yield Significant Savings, Stronger Communities*, which examines how much the country could save by strategically investing in community-based disease prevention programs. The report concludes that an investment of \$10 per person per year in proven community-based programs to increase physical activity, improve nutrition, and prevent smoking and other tobacco use could save the country more than \$16 billion annually within five years. This is a return of \$5.60 for every \$1 spent. The economic findings are based on a model developed by researchers at the Urban Institute and a review of evidence-based studies conducted by the New York Academy of Medicine. The researchers found that many effective prevention programs cost less than \$10 per person, and that these programs have delivered results in lowering rates of diseases

that are related to physical activity, nutrition, and smoking cessation. The evidence shows that implementing these programs in communities reduces rates of type 2 diabetes and high blood pressure by five percent within two years; reduces heart disease, kidney disease, and stroke by five percent within five years; and reduces some forms of cancer, arthritis, and chronic obstructive pulmonary disease by 2.5 percent within 10 to 20 years, which, in turn, can save money through reduced health care costs to Medicare, Medicaid and private payers.

#### **Chronic Diseases**

Chronic diseases, most of which are preventable, account for 70 percent of deaths in the U.S. and approximately 75 percent of health care spending. In the U.S., two-thirds of adults are obese or overweight, and approximately 23 million children are obese or overweight. CDC's Division of Nutrition, Physical Activity and Obesity (DNPAO) provides funding to states to create, implement and monitor a nutrition, physical activity and obesity state plan. In the previous grant cycle, 28 grantees were supported, but CDC was only able to award funds to 23 states in the new cycle. Similarly, funding levels for the Division of Adolescent and School Health's (DASH) Coordinated School Health Program, which assists states in improving the health of children through a program that engages families and communities and develops healthy school environments, have only been sufficient to support 23 grantees. To begin to mitigate the obesity epidemic, we need chronic disease prevention and promotion programs in all 50 states. That will require \$90 million for DNPAO to fund all approved states at the level at which they applied for funds and at least an additional \$20 million for DASH's School Health program to fund all states that have been approved.

Another important anti-obesity program is the Healthy Communities Program. Healthy Communities grants support communities, cities, states and tribal entities to implement health promotion programs and community initiatives. TFAH supports at least \$30 million for the Healthy Communities Program. Yet, funding for this program has decreased dramatically over recent years, from \$43 million in FY 2007 to \$22.7 million in the FY 2009 omnibus appropriations bill. We support restoration of Healthy Communities funding because action at the local level is essential if we are to begin to mitigate the obesity epidemic.

#### **Preparing for Public Health Emergencies**

In December of last year, TFAH released its annual "Ready or Not" report on the nation's preparedness for a catastrophic event. Unfortunately, there are many areas where the U.S. remains woefully under-prepared. This is particularly alarming in light of the fact that state and local health departments cut an estimated 11,000 jobs in the past year, and 10,000 vacancies are expected to remain unfilled within the next year. That is why we are deeply concerned that the greatly diminished federal support for an all-hazards approach to preparedness will put the progress we have made at risk.

Funding for the Public Health Emergency Preparedness (PHEP) Cooperative Agreements to states and localities -- where public health actually happens -- has been cut in recent years. With these funds, local health departments have enhanced their disease surveillance systems and trained their staff in emergency response. Over 90 percent of local health departments have developed mass vaccination and prophylaxis planning, conducted all-hazards preparedness training, and implemented new or improved communication systems. All states have established

the infrastructure necessary to evaluate urgent disease reports and to activate emergency response operations 24 hours a day. Yet despite this progress, challenges remain. In its 2008 progress report, CDC noted that 31 state public laboratories reported difficulty recruiting qualified laboratory scientists, and no state public health laboratory can rapidly identify priority radioactive materials in clinical samples. To continue our commitment to emergency preparedness, sustainable funding is necessary. TFAH recommends \$1 billion for upgrading state and local capacity, an increase of \$253 million over the FY 2009 level. We also recommend \$596 million for ASPR's Hospital Preparedness Program (HPP), an increase of \$208 million over the FY 2009 level, to improve the capacity of our hospitals and other supporting healthcare entities to respond to bioterrorist attacks, infectious disease epidemics, and other large-scale emergencies by enabling hospitals, EMS and health centers to plan a coordinated response.

Another important program for our nation's preparedness is the Biomedical Advanced Research and Development Authority (BARDA). BARDA was established in 2006 to help jumpstart a new cycle of innovation in vaccines, diagnostics and therapeutics to combat health threats. BARDA provides incentives and guidance for research and development of products to counter bioterrorism and pandemic flu and manages Project BioShield, which includes the procurement and advanced development of medical countermeasures for chemical, biological, radiological, and nuclear agents. The FY 2009 omnibus appropriations bill provided \$275 million for BARDA, an increase of approximately \$173 million over FY 2008 levels. TFAH applauds Congress' continued commitment to BARDA but notes that a significant increase in funding would be necessary to support the successful development of medical countermeasures. TFAH requests \$500 million for BARDA in FY 2010, with two years of fiscal availability, noting that over the next few years, higher funding levels must be allocated and sustained.

#### **Public Health Workforce**

In order to prepare for any public health emergency, it is necessary to have a well-trained workforce. The Office of the Civilian Medical Reserve Corps, located in the Office of the Surgeon General, supports local public health and helps provide for an adequate supply of volunteers in the case of a Federal, State, local, territorial or tribal public health emergency. Medical Reserve Corps (MRC) units are community-based and serve as a way to locally organize and utilize volunteers desiring to prepare for and respond to emergencies and promote healthy living throughout the year. TFAH supports \$15 million for the Office of the Civilian Volunteer Medical Reserve Corps to enable the MRC to award more capacity building grants, which local units use for a variety of purposes, such as purchasing equipment, training, purchasing uniforms and providing salaries for coordinators. Funding will also help the MRC to develop federal deployment capacity for use during public health emergencies.

#### **Bolstering the Nation's Ability to Detect and Control Infectious Diseases such as Pandemic Influenza**

Since 2003, scientists have become increasingly concerned that the H5N1 strain of avian influenza could become more contagious among humans and mutate into a strain against which humans have little or no immunity, sparking a global pandemic. H5N1 has infected millions of birds and poultry worldwide and resulted in over 250 deaths in humans, with a human case fatality rate of over 60 percent. In FY 2006, Congress appropriated \$5.6 billion to the Department of Health and Human Services (HHS) for emergency and agency funding for

pandemic preparedness. The funding has been used for stockpiling enough antiviral drugs for the treatment of more than 50 million Americans, licensing a pre-pandemic influenza vaccine, developing rapid diagnostics and completing the sequencing of the entire genetic blueprints of 2,250 human and avian influenza viruses.

TFAH was disappointed that the \$870 million requested by the Bush Administration for FY 2008 was ultimately dropped from the American Recovery and Reinvestment Act. This funding was to be allocated for one-time pandemic preparedness activities, including acquiring vaccine, purchasing antiviral medications, and accelerating research and development for rapid diagnostic tests. We were pleased that the FY 2009 omnibus provided \$507 million to be used to build vaccine production capacity, maintain a ready supply of eggs for the production of vaccine, and enable HHS to purchase medical countermeasures for its critical employees and contractors, as well as the Indian Health Service population. In FY 2010, we urge Congress to provide the full \$870 million that was initially requested for FY 2008.

Additionally, TFAH recommends continuing to fund ongoing pandemic preparedness activities at the CDC, National Institutes of Health (NIH), Food and Drug Administration (FDA) and the Office of the Secretary. The one major gap in pandemic preparedness that has not been addressed recently through the appropriations process is funding for states and localities with respect to pandemic preparedness. HHS has released the final installment of the \$600 million appropriated in FY 2006 for state and local pandemic preparedness activities. This funding has been used to conduct statewide pandemic influenza preparedness summits, assess and address preparedness gaps, develop antiviral distribution plans, review and update state pandemic plans, and conduct exercises at the state and local levels, including mass vaccination using seasonal flu clinics, school closures and medical surge. These are clearly not one-time activities. A recurring, sustained funding source is needed for ongoing state and local pandemic preparedness activities. To further exacerbate the current situation, as referenced earlier, over the past few years, states and localities have experienced major cuts in CDC's Public Health Emergency Preparedness Cooperative Agreements. We are concerned that these cuts, in addition to the elimination of the state and local pandemic preparedness funds, will limit states' ability to continue to conduct exercises. As a result, we urge the Subcommittee to provide \$350 million in recurring, annual funding for state and local pandemic preparedness activities.

#### **Environmental Health**

One additional area of interest for TFAH is the connection between our environment and our health. For more than 30 years, the Environmental Health Laboratory of the National Center for Environmental Health has been performing biomonitoring measurements. Biomonitoring is the direct measurement of people's exposure to toxic substances in the environment. By analyzing blood, urine, and tissues, scientists can measure actual levels of almost 300 chemicals in people's bodies, and determine which population groups are at high risk for exposure and adverse health effects, assess public health interventions, and monitor exposure trends over time. In FY 2009, the Environmental Health Laboratory was funded at \$42.7 million. Additional funds are needed to upgrade facilities and equipment and to bolster the workforce. Of the suggested \$19.6 million increase, \$10 million would be used extramurally to support state public health laboratory biomonitoring capabilities. An additional \$7.6 million would be used for intramural activities, including increasing the number of chemicals CDC measures, providing training and quality

assurance for state laboratories awarded biomonitoring funds; and increasing the number of studies used to assess health effects associated with exposure to environmental chemicals. Additionally, \$2 million would support the *National Report on Biochemical Indicators of Diet and Nutrition in the U.S. Population*.

TFAH is also concerned about the potential health effects of climate change, including injuries and fatalities related to severe weather events and heat waves; infectious diseases; allergic symptoms; respiratory and cardiovascular disease; and nutritional and water shortages. TFAH was appreciative of the \$7.5 million included in the omnibus for a Climate Change Program at CDC. To expand this program, for FY 2010, TFAH recommends \$17,500,000 to enable CDC to bolster its climate change staff, conduct climate change research and begin to work with state and local health departments on capacity building for climate change and health preparedness. Ultimately, \$50 million is needed to develop a credible and effective Climate Change Program that would fund all 50 states and certain large city health departments to implement a national climate preparedness program.

To track the health effects of climate change, it is important to enhance our surveillance capabilities, including expanding CDC's National Environmental Health Tracking Network and its Global Disease Detection Program. The National Environmental Health Tracking Network enhances our understanding of the relationship between environmental exposures and the incidence and distribution of disease, including potential health effects related to climate change. Health tracking, through the integration of environmental and health outcome data, enables public health officials to better target preventive services so that health care providers can offer better care, and the public will be able to develop a clear understanding of what is occurring in their communities and how overall health can be improved. Since 2002, Congress has provided funding for pilot programs in some states and cities. The National Network is launching in 2009. With that in mind, TFAH recommends providing \$50 million for CDC's Environmental and Health Outcome Tracking Network, an increase of \$19 million over the FY 2009 level, to expand it to additional states and support the continued development of a sustainable Network.

Finally, TFAH supports the expansion of CDC's Global Disease Detection (GDD) Program. Despite remarkable breakthroughs in medical research and advancements in immunization and treatments, infectious diseases are undergoing a global resurgence that threatens health. Worldwide, infectious diseases are the leading killer of children and adolescents and are one of the leading causes of death for adults. It is estimated that newly emerging and re-emerging infectious diseases will continue to kill at least 170,000 Americans annually. CDC's GDD Program helps recognize infectious disease outbreaks, improve the ability to control and prevent outbreaks, and detect emerging microbial threats. To address the magnitude and urgency of emerging and resurging diseases, TFAH recommends \$56 million for the GDD Program, an increase of \$22 million over the FY 2009 level. Funding will increase the number of GDD centers across the globe and bring some existing centers to full capacity.

Mr. Chairman, thank you again for the opportunity to submit testimony on the urgent need to enhance federal funding for public health programs which can save countless lives and protect our communities and our nation.



**Written Testimony Submitted to  
The House Appropriations Committee,  
Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies  
by Michael L. Lomax, Ph.D.  
President and CEO of UNCF  
May 1, 2009**

Mr. Chairman and distinguished Members of the subcommittee, I am Dr. Michael L. Lomax, President and CEO of UNCF-the United Negro College Fund. I want to thank you for allowing me to submit funding recommendations and priorities relevant to the FY10 Labor-HHS-Education Appropriations bill.

**BACKGROUND**

Before going forward with my remarks, I would like to show my gratitude to the subcommittee for its historic support of Historically Black Colleges and Universities (HBCUs). This subcommittee has supported our national efforts to ensure that the underrepresented groups of America are afforded the same opportunities in education, labor, and research development as their counterparts. The Labor, Health & Human Services, Education subcommittee has the ability to impact the students, faculty and communities in the areas we hold dear and involve the partners and beneficiaries of the federally funded programs intended to expand educational opportunities for all Americans, many of whom come from underserved communities. Under the jurisdiction of this illustrious subcommittee, you have assisted greatly in providing expanded educational opportunities for all Americans.

The universe of HBCUs includes two- and four-year, public and private, single-sex and co-ed institutions, located primarily in southern states. They enroll over 13% of all African American students nationwide. HBCUs also vary demographically. Although HBCU student populations are primarily black, the institutions enroll significant numbers of non-black students.

Statistically, HBCUs graduate a preponderant share of all black Americans receiving degrees. While comprising only three percent of the nation's 4,197 institutions of higher learning, the 103 HBCUs are responsible for producing approximately 25% of all bachelor's degrees, 10% of all master's degrees and 26% of all first professional degrees earned by African Americans annually.

UNCF institutions are a critical component and significant subset of the larger community of HBCUs. Specifically, UNCF is the national fundraising and advocacy representative of 39 private historically black colleges and universities. There are more than 350,000 persons who are counted as alumni of UNCF member colleges and universities. Our alumni include persons such as Dr. Martin Luther King, Jr., three former Surgeons General, Brown University President Ruth Simmons, at least 18 current Members of Congress and many other distinguished persons.

UNCF- the nation's oldest and most successful minority higher education assistance organization, fulfills its primary goal by increasing opportunities for access to higher education. During its 65-year existence, UNCF has raised more than \$3 billion to support its historically black college and university member institutions and administered nearly 300 programs, including scholarships, mentoring programs, summer enrichment, study abroad, curriculum, faculty, and leadership development. Today, UNCF supports more than 65,000 students at over 900 colleges and universities across the country.

UNCF has played, and continues to play a distinguished role as an advocate for higher education institutions whose historical mission was, and continues to be, the education of black people. UNCF continues to provide unparalleled leadership in assessing, developing and implementing Federal policy and programmatic priorities that are of significance to its membership and the nation as a whole.

In fact, UNCF member institutions represent, for example, just 1.4 percent of all four-year colleges and universities, but they produce 5.6 percent of all baccalaureate degrees awarded to African Americans, four times the expected impact.

UNCF stands ready to connect and leverage its strengths in support of President Obama's goal of significantly increasing college completion rates by 2020. UNCF has articulated its own goal of doubling the number of college graduates annually produced by our 39 member institutions to 16,000 by 2020. In the short term, *we endeavor to increase the number of students who annually graduate from member institutions with bachelor's degrees by just over 50 percent by the spring of 2014, from 7,800 to 12,000.* Achieving these goals requires significant increases in enrollment and graduation rates, larger and more scholarships awarded, aggressive faculty development programming, greater alumni support, and better, more accessible venues to share best practices across the UNCF consortium and beyond. More relevantly, meeting this goal will require the robust investment and support of this subcommittee.

We recognize that working with the Administration and Congress will continue to be particularly challenging in a budget-constrained environment where more diverse students with unique academic and familial circumstances are dependent upon need-based aid. In keeping with this, UNCF endorses the following policies and positions as the focal point of its legislative agenda for the first session of the 111<sup>th</sup> Congress. These recommendations continue a basic commitment to enrolling, nurturing, and graduating students, some of whom lack the social, educational, and financial advantages of other college bound populations. This agenda reflects what is needed to level the playing field for both UNCF member schools and students as we continue pursuing educational excellence.

Concerning FY10, programs authorized under Titles II, III and IV of the Higher Education Act (HEA) are of particular relevance and importance to UNCF.

- Title II Augustus F. Hawkins Centers of Teaching Excellence -- \$50 million

The Administration has given a high priority to increasing the number of teachers, especially in low-income, high-need communities. According to the National Center for Education Statistics,

America will need two million new teachers over the next decade because of the retirement of veteran teachers, increased student enrollment, more rigorous qualification standards, and advances in teaching and learning techniques specifically known to benefit diverse student learners. These shortages are exacerbated in high-poverty urban and rural districts, and among mathematics and science teachers. To the latter point, for instance, one recent study by the Business-Higher Education Forum estimates that the country will need 285,000 new math and science teachers by 2015.<sup>1</sup>

Teacher development is a capability that is part of both UNCF's traditional capacity and a focus of its most recent work. HBCUs have been particularly successful at producing graduates who enter the teaching profession. Among the nation's African American public school teachers, approximately 50% have earned a degree from an HBCU.

- Title III, Part B, Strengthening Historically Black Colleges and Universities -- \$400 million (Section 323) and \$100 million (Section 326)

This program has been, and continues to be, the principle source of institutional assistance for HBCUs. Congress first funded this program in FY87. Since its inception, the Title III, Part B (Sections 323 & 326 and C of the Higher Education Act entitled "Strengthening Historically Black Colleges and Universities") program has succeeded in supporting strategic planning initiatives, academic program enhancements, administrative and fiscal management, student services, physical plant improvements, and general institutional development.

Significant increases in funding to Title III Part B must be made over the next three years in order to sustain and enhance the quality of HBCUs, and to meet the national challenges associated with global competitiveness, job creation and changing demographics. For FY10, UNCF requests \$400 million to support Section 323 and the inclusion of report language evidencing the subcommittee's commitment to significantly increasing funding for this program over the next 3-5 years.

- Title IV -- UNCF joins the Student Aid Alliance in supporting language included in the American Recovery and Reinvestment Act (ARRA) increasing funding for the maximum Pell award to \$5,500, as well as other increases for Title IV proposed by President Obama

Title IV, Student Assistance, programs such as Pell, Work-Study, SEOG, TRIO, and other programs authorized under Title IV are critical to ensuring access and achievement. More than two-thirds (68 percent) of all HBCU students, and as much as 82 percent of students at UNCF institutions, come from families with incomes below \$50,000, compared to just 31 percent of students who attend other four-year colleges and universities. Furthermore, 39 percent of all HBCU students and 55 percent of UNCF students come from families with incomes under \$25,000, compared to 12 percent of all other students who attend colleges. Moreover, 93 percent of the UNCF student population receives financial assistance.<sup>2</sup>

<sup>1</sup> <http://www.bhef.com/solutions/anamericanimperative.asp>

<sup>2</sup> See Tazewell Hurst and Fevan Negga, *UNCF Statistical Report 2003*, Frederick D. Patterson Institute, 2004, p.20 and Alexander W. Astin, W.S. Korn, J.A. Lindholm, K.M. Mahoney, V.B. Saenz & L.J. Sax, *The American Freshman: National Norms for Fall 2003*, Higher Education Research Institute, UCLA, 2004.



Thirty years ago, student financial aid packages were built upon a foundation of a Pell Grant, with loans as a final component to address unmet need. During the last ten years alone, loan aid funding has more than doubled making loans the most readily available form of financial assistance. Currently, loans make up the bulk of student financial aid packages, comprising 58 percent of all award packages compared to 42 percent in grants and other non-loan campus-based aid (73 percent of all UNCF students receive Stafford loans; 59 percent receive Pell Grants; 25 percent receive SEOG; and 18 percent receive Work Study).

In terms of providing real purchasing power in education for low-income students, when adjusted for inflation, the Pell Grant is worth only 77 percent of its value in 1975 dollars. Because of Pell's diminished value and the relatively high unmet need of low-income students, the overarching impact of the policy shift from need-based grant aid to loans has meant that many more low-income students are forced to assume greater loan debt and to work more in order to finance their postsecondary education.

UNCF supports President Obama's proposal to make Pell Grants an entitlement so that future generations of students can rely on Pell Grant support for the college education they need and the nation needs them to have. We understand that many details still need to be worked out, but in addition to expressing our support for the President's proposal, we to urge you to make sure that any legislation that includes the President's Direct Loan plan also includes federally funded direct-loan-processing support for small schools like those that belong to UNCF.

It is not uncommon for some of our colleges to have just three or four person financial aid departments. Small schools have for years depended for processing on the private lenders, whose role under the President's proposal will be diminished or eliminated, and they will find it difficult or impossible to absorb the administrative responsibilities that a Direct Loan plan will entail. They will also be hard pressed to afford the technology systems that will be needed to process direct student loans.

Finally, nothing is more important to UNCF, its students and its member colleges and universities than the passage and success of the President's college affordability proposal. UNCF and our member schools have, among them, many years of experience making a college education a reality for low-income students and the colleges they attend. My staff and I, and the presidents of our member schools, stand ready to work closely with you and your committee to craft a plan that will work for all the young people who want and deserve a college education.

#### **Labor – HHS – Education FY10 RECOMMENDATION**

The chart that follows outlines more specifically the relevant programs and funding levels for which we seek your support.



## HBCU COALITION FY 2010 BUDGET RECOMMENDATIONS<sup>7</sup>

DEPARTMENT/AGENCY PROGRAMS	FY09 UNCF REQUEST	FY10 PRESIDENT'S REQUEST	FY10 COALITION REQUEST	FY10 PRESIDENT'S REQUEST
<b>DEPARTMENT OF EDUCATION</b>				
<b>STUDENT FINANCIAL ASSISTANCE</b>				
Federal Pell Grant (Maximum Award)	\$14,215 million	\$16,851 million	\$17,348 million	\$17,335 million
Federal TRIO	(\$4,731) <sup>8</sup>	(\$4,800) <sup>9</sup>	(\$5,100)	(\$4,860) <sup>10</sup>
Supplemental Educational Opportunity Grants	\$828 million	\$828 million	\$1 billion	\$968 million
Leveraging Educational Assistance Partnership Program	\$757.5 million	\$0	\$1 billion	\$757,465 million
Federal Perkins Loans	\$63.85 million	\$0	\$100 million	\$63,852 million
Federal Family Education Loans (credit activity)	\$64.3 million	\$980 million	\$125 billion	\$980 million
Proposal on Mandatory Outlays	\$4,698.5 million	\$0	\$100 million	\$300 million
Academic Competitiveness Grants/SMART Grants	\$395 million	\$1,817.5 million	N/A	TBD
GEAR UP	\$303.4 million	\$960 million	\$1.2 billion	TBD
Thurgood Marshall Legal Education Opportunity Program	\$2,895 million	\$303.4 million	\$350 million	\$312.12 million
GAANN	\$29.5 million	\$0	\$5 million	\$5 million
Javits Fellowships	\$9.5 million	\$32.5 million	\$31.03 million	\$41 million
Mink Fellowships	N/A	\$9.8 million	\$9,687 million	\$16 million*
		N/A	N/A	\$15 million

7 The Coalition Requests for FY2010 reflect the following priorities, not in rank order: (1) Title II, Teacher Quality Enhancement and the Augustus F. Hawkins Centers of Excellence; (2) Title III, Part B, Strengthening HBCUs, including Sec. 326, Historically Black Graduate Institutions; (3) HBCU Capital Financing; (4) Federal Pell Grants and Federal TRIO; (5) Minority Science and Engineering Improvement Program; (6) the HBCU Department of Energy Initiative; (7) Title VII, HBCU/PIB Masters Programs; (8) Minority Institutions Digital & Wireless Technology Opportunity Act Program; (9) HUD HBCU CDBG Development Program; (10) Comprehensive HBCU Historic Preservation Program; and (11) Title VI, Part C, Institute for International Public Policy (IIPP).

8 Requesting funding for the TRIO program.

9 Requesting funding for the Supplemental Educational Opportunity Grants program.

10 Includes \$4,410 discretionary funding and \$480 in mandatory funding from the College Cost Reduction Act.

\* Consistent with levels recommended by the Student Air Alliance



DEPARTMENT/AGENCY PROGRAMS	FY19 OMBUS REQUEST	FY19 PRESIDENT'S REQUEST	FY19 OMBUS REQUEST	FY19 PRESIDENT'S REQUEST
DEPARTMENT OF EDUCATION AID FOR INSTITUTIONAL DEVELOPMENT/PROGRAM DEVELOPMENT				
Title III, Part A	\$78.1 million	\$78.1 million	\$126.3 million	\$126.3 million
PBI (Sec. 318)	\$15 million	\$13 million		\$25 million
Title II, Part B, Section 323	\$323.095 million	\$238.095 million <sup>11</sup>	\$345.0 million	\$1 billion <sup>12</sup>
Discretionary Funding	\$238.095 million	\$153.095 million	\$280 million	N/A
Mandatory Funding	\$85.0 million	\$85.0 million	\$65.0 million	
Title III, Part B, Section 326	\$56.903 million	\$56.903 million	\$75 million	\$100 million
Title II, Part C, Endowment Grant	\$0	\$0	\$25 million	\$25 million
Title III, Part D, HBCU Capital Financing	\$185 million	\$354 million	\$308 million	\$15.354 million <sup>13</sup>
Minority Science and Engineering Improvement Program (MSEIP)	\$8.58 million	\$8.58 million	\$20 million	\$20 million
Title VI, Institute for International Public Policy (IIPP)	\$1.67 million	\$1.67 million	\$3 million	\$3.2 million
Title VI, International Education (domestic/overseas)	\$107.3 million	\$107.3 million	\$132.2 million	TBD
Title VII, Masters Degree Programs at HBCUs and PBIs	\$0	\$0	\$0	\$15 million

<sup>11</sup> \$85 million out represents an offset of additional mandatory funding secured for Section 323 in the College Cost Reduction Act.  
<sup>12</sup> Recent economic developments and proposals outlined by Congress and the Administration require HBCUs to be more actively engaged and accelerate efforts to educate the populations we serve.  
<sup>13</sup> Increased FY10 funding will support additional administrative costs associated with increased loan authority authorized by the Higher Education Opportunity Act (P.L. 110-315), and subsidies required by the Department of Education and the Department of Treasury.



DEPARTMENT/AGENCY FUND CODES	FY08 AMBUDS REQUEST	FY08 PRESIDENT'S REQUEST	FY08 AMBUDS REQUEST	FY08 PRESIDENT'S REQUEST
<b>DEPARTMENT OF EDUCATION OTHER</b>				
Title II, Teacher Quality Enhancement Grants	\$33.7 million	\$0	\$190 million	\$50 million
Augustus F. Hawkins Centers of Teaching Excellence	\$0	\$0	\$0	\$50 million
Howard University	\$233.2 million	\$233.2 million	\$237.4 million	\$234.97 million
TEACH Grants				TBD
Office of Civil Rights Comparability and Competitiveness Initiative				\$8 million
<b>OTHER DEPARTMENTS AND AGENCIES DEPARTMENT OF HEALTH &amp; HUMAN SERVICES</b>				
Health Professionals for Diversity/HRSA	\$68.7 million	\$0	\$117.6 million	\$96.843 million
Minority Centers of Excellence	\$12.8 million	\$0	\$33.6 million	\$20.602 million
Health Careers	\$9.8 million	\$0	\$35.6 million	\$19.133 million
Opportunity Program Scholarships for Disadvantaged Students	\$45.8 million	\$0	\$47.128 million	\$45.842 million
Faculty Loan Repayment	\$1.27 million	\$0	\$1.3 million	\$1.266 million
NIH National Center on Minority Health Disparities	\$199.668 million	\$199.569 million	\$210.746 million	\$205.95 million
NIH Research Centers at Minority Institutions	\$0	\$53.58 million	\$55 million	N/A
PHS Office of Minority Health	\$48.7 million	\$42.7 million	\$65 million	\$52.965 million
NIH Minority Access to Research Centers (MARCC)	\$0	TBD	\$35 million	N/A
NIH Minority Biomedical Research Support (MBRS)	\$0	\$110.4 million	\$120 million	N/A
National Youth Sports Program	\$0	\$0	\$18 million	\$0
				TBD

Receipt Reply requested:

To: House Committee on Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies

Email: [lh.appropriations@mail.house.gov](mailto:lh.appropriations@mail.house.gov)

From: Jay Alexander, Founder of the grassroots citizens action group "We Can Take It!"

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Contacts:

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Associates: Ken Bynum in Jay , FL (850) 675 6108 and Bill Reed in Altus, OK (580)-480-0519

Website: [www.wecantakeit.org](http://www.wecantakeit.org)

Re: Written Public testimony for the Reactivation of the Civilian Conservation Corps (CCC) on Native American Lands, Public (Federal and Military Reservation) Lands.

We respectfully request amount of \$500 million dollars to be appropriated over a period of ten years for the reactivation of the CCC on sovereign Native American Lands. Monies would be distributed to the Native Tribes with oversight provided by the Departments of the Interior and Agriculture., to fund and carry out shovel ready work projects similar to the template of FDR's CCC under a separate Indian Division for Native American Lands. The CCC would enable enrollement for all unemployed First American adults aged from 17 to 35. They would be able to work from their homes on infrastructure and ecosystem work projects on their sovereign tribal and adjacent lands. The CCC program worked for our first Americans in the past and can work for the entire nation again.

We also request the appropriation up to of 5 billion a year or to 50 billion over next decade (to include the allotment for the request above for our First Americans) for employment recovery for the rest of our Nation's fit young Americans and Veterans. (The estimated cost of the program is based on the 1942 dollar.) The program would again be conducted by the the Departments of Interior, Agriculture. the US Army (Defense) and the Department of Veterans Affairs and Labor, to avoid the creation of another government bureaucracy. This program would provide shovel ready projects and put up to a half a million enrollee work boots on the ground every year.

Shovel Ready projects as in FDR's time, work projects in general include forest, park , watershed, erosion control and grazing management. New projects would involve vocational training in solar and wind power, training and work for hazardous waste removal and projects involving phytoremediation, organic farming, new wildlife habitat and new areas for recreation.

The requested appropriation would include the purchase of acreage adjacent to government owned lands for the purpose of creating new green space for wildlife habitat and recreation.

Seventy-six years ago, the 73rd Congress and President Roosevelt faced a similar situation banking crisis. FDR was, personally interested in preserving the environment and providing temporary employment for the nation's youth and veterans. Legislation to establish the U.S. Civilian Conservation Corps was also introduced March 21, 1933 in a message to Congress he wrote...

"It is essential to our recovery program . . . the first of these measures . . . can and should be

immediately enacted. I propose to create a civilian conservation corps to be used in forestry, the prevention of soil erosion, flood control and similar projects . . . but also as a means of creating future national wealth. . . . More important, however, than the material gains from their labors will be the moral and spiritual value of such work."

The president himself shepherded the legislation through both houses. It was signed into law 10 days later. Over the next nine years, almost 4 million young men were put to work reclaiming the country's natural resources. The men lived in government camps, food and clothing were provided, the Army supervised the camps, and the men were required to send 80 percent of their pay of \$30 back to their families. (\$30 in 1933 is equivalent to \$451.48 in 2007.) It became the largest mobilization of civilian workers and the most popular government program in American History. In 1942, the 77th congress cut the CCC funding, but the program was never abolished by the 77th Congress and it only needs reactivated and the dust removed from the books.

The current rise in unemployment and poverty among unskilled young adults, war veterans (25% of the entire US homeless population today is our Veterans) and Native Americans (many reservations have as much as 50% unemployment). Global warming and our environmental need our stewardship. Our infrastructure is now rated at a D grade by the American Society of Engineers.

The time is right to reactivate the US Civilian Conservation Corps for our First Americans. It is by far the best "Shovel Ready" program to date to put thousands of work boots on the ground within a matter of weeks. This program is proven cost effective and would give the U.S. Taxpayer more 'Bang for the Buck!'

"We Can Take It!" urges the House Committee on Appropriations Subcommittee on Interior, Environment, and Related Agencies to give serious consideration to remobilize this 'Shovel Ready' workforce to salvage First American Lands and to salvage the lives of many young Native American citizens and Native American Veterans, now in jeopardy. They would be given jobs in the CCC if they qualify from the state of Maine to the US Territory of American Samoa.

Similar federal, state, and local government work programs for Native Lands should be re-absorbed into the Civilian Conservation Corps to avoid waste in overlap, fraud and abuse and insure government accountability to the people of the United States.

This program would now be open to women and also offer individuals an alternative to military service. Those who fulfill their obligation would have access to the GI Bill. The military would have fit men and women to enter if they choose to further serve their country.

Dr Neil M. Maher, author and associate professor of history at Rutgers University, said, "Brazil has recently begun looking back to Franklin Roosevelt's CCC to help solve that country's economic and environmental problems. Plagued by high unemployment rates approaching ten percent, local, state, and federal governments in cooperation with non-governmental organizations and corporations have begun putting jobless Brazilians to work planting trees. The goal of Brazil's CCC-like program, which the Nature Conservancy helped initiate, is to plant one billion trees over the next ten years across the country's Atlantic Forest. Rather than funding the program solely by increasing taxes and federal spending, Brazil will rely on novel market mechanisms including the sale of sequestration vouchers on the international carbon market, obtained through the program's reforestation efforts, as well as the collection of water use fees in the reforested regions. Similar tree-planting programs reminiscent of FDR's CCC are also now operating in China along the Yangtze River and through Wangari Maathai's Greenbelt Movement in Kenya. Even war-torn Afghanistan has created its own "Afghan Conservation Corps. The United States needs to follow suit, and Barrack Obama's first 100 days in office is one place to start. Like Roosevelt, Obama should ask Congress to create a Civilian Conservation Corps, but with a twist. Along with planting trees, this new and improved Corps should put young Americans,

both men and women, to work planting windmills across the former Dust Bowl, solar energy panels throughout the Sunbelt, and energy-efficient biofuels on farms in every corner of the country, all in an effort to reduce both unemployment and the production of greenhouse gasses that lead to global warming. While Roosevelt funded the New Deal's CCC with federal dollars, public spending for Obama's new program could be greatly reduced through market mechanisms like those embraced by Brazil; by collecting carbon vouchers and water use fees from the new program's reforestation efforts, and by selling clean, green energy generated from new windmills, solar panels, and biofuels. The young men and women enrolling in this market-driven Corps would also benefit. Not only would they gain valuable training, skills, and experience in the expanding green economy, but they could also be encouraged to put their enrollment stipend towards a college education."

The US Civilian Conservation Corps over the years would enroll young men, women, and veterans. They will all gain strong civic, work and conservation ethics. They would also be trained and skilled in disaster relief and on call. This program would be of the people, by the people, and for the people.

Contact us for additional information and we are available for any future hearings.

Thank you.

Jay Alexander

Founder of WE CAN TAKE IT

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